The University of San Francisco
USF Scholarship: a digital repository @ Gleeson Library | Geschke Center

Doctor of Nursing Practice (DNP) Projects

Theses, Dissertations, Capstones and Projects

2009

The Experience of African American Hospice Patient/Family with Board Certified Music Therapy as a Component of their Plan of Care

Elizabeth Joy Gifford
University of San Francisco, lgiffman1@aol.com

Follow this and additional works at: https://repository.usfca.edu/dnp

Part of the Nursing Commons

Recommended Citation

Gifford, Elizabeth Joy, "The Experience of African American Hospice Patient/Family with Board Certified Music Therapy as a Component of their Plan of Care" (2009). *Doctor of Nursing Practice (DNP) Projects*. 14.
https://repository.usfca.edu/dnp/14

This Project is brought to you for free and open access by the Theses, Dissertations, Capstones and Projects at USF Scholarship: a digital repository @ Gleeson Library | Geschke Center. It has been accepted for inclusion in Doctor of Nursing Practice (DNP) Projects by an authorized administrator of USF Scholarship: a digital repository @ Gleeson Library | Geschke Center. For more information, please contact repository@usfca.edu.

COMPREHENSIVE EXAM

Section I: Introduction

Statement of the Problem

Although 60% of African Americans in the United States have stated that they would want hospice care when they are dying (AARP, 2003), they only comprise 8% of all hospice enrollees (NHPCO, 2007), despite the fact that they represent 13% of the total population in this country (U.S. Census Bureau, 2008). In fact, hospice care in this nation has always been underutilized by African Americans (Connor, Elwert, Spence, & Christakis, 2008).

In the San Francisco Bay Area, among Medicare-certified hospice agencies that submit data to the State of California, only 2% of all the hospice enrollees in 2007 were African American (OSHPD, 2008). In the Oakland Bay Area, African Americans represent 36% of the general population, yet only 15% of the patients of Pathways Hospice, which serves the Oakland population (Allscripts Home Care, 2009). Even among those African Americans who are enrolled in hospice care, there is a significantly higher rate of withdrawal than there is among other ethnic groups (Johnson, Kuchibhatala, Tanis, & Tulsky, 2008).

One of the reasons that African Americans avoid hospice care—and tend to avoid medical care of any kind, for that matter—is the distrust they have toward the health-care system in general because of its historical abuses of them in this nation. For example, the Tuskegee experiments in the 1960s, testing the progression of syphilis, let the disease take its course in African American men without the intervention of penicillin, which was readily available. Even as recently as 2000, the Pfizer Corporation, a huge pharmaceutical company, used Nigerian children who had bacterial meningitis to test one of their drugs without the consent of the children or their parents (*Abdullah v. Pfizer Inc*., 2003). Thus, the skepticism of the African American population toward the American health-care system has objective foundations. In fact, this skepticism has even deeper roots in the whole history of racism in this nation, including slavery and economic exploitation (Searight & Gaffrod, 2005).

When it comes to hospice care, many African Americans avoid it for two contradictory reasons: (1) it does too little; and (2) it does too much. Hospice care does too little, in this view, because it only treats symptoms of illness—in particular, pain—rather than causes (Miller, 2008). Thus, grandma is made to feel as comfortable as possible in her last days, but nothing more is done to prolong her life. On the other hand, for some African Americans, hospice care does too much, in the sense that it alleviates pain when the whole point of life is the nobility of suffering (Omonzejele, 2008). Many African Americans have, in fact, coped with the injustices perpetrated against them over the centuries by believing that there is nobility in suffering (Born, Greiner, Butler, & Ahluwalia, 2004; Fife, 2009).

Yet another reason that African Americans underutilize hospice care is that they have little knowledge of the wide range of services offered by hospice agencies, especially since there have been so few efforts to market hospice care to this community (Fife, 2009). For example, most African Americans—perhaps as many as 85%—are unaware that Medicare covers the cost of hospice care (AARP, 2003). In other words, African Americans are already partly paying for hospice care as taxpayers, but are not receiving its benefits in equal proportion.

Significance of the Problem

There is a huge amount of unnecessary suffering by African Americans who avoid hospice care. First, those who go to or remain in hospitals, choosing acute care interventions, essentially prolong their own dying, with all the physical, mental, and financial suffering that that entails. Second, those who decline both hospital care *and* hospice care tend to experience pain and suffering that could be alleviated. On a purely humanitarian level, therefore, it is socially desirable to prevent human suffering. Furthermore, underutilization of hospice care and overutilization of hospital services drive up health-care costs unnecessarily.

Statement of Purpose

Dame Cecily Saunders, the founder of the modern hospice movement, saw the need to bring together the best possible medical care with the best possible spiritual care to meet the needs of humans living with expected terminality. Her goal was not only to help persons to die peacefully, but to live right up until death (Chochinov, 2006; Zahovaeva, 2007). The broad purpose of the present project was to increase the percentage of African Americans who utilize hospice care in this country. The narrow purpose of this project was to attempt to effect such an increase at one hospice care agency in an area with a sizable African American population. This writer's inspiration, based on her past nursing experiences, was that the most likely magnet to attract this population to hospice care would be music—specifically music therapy administered by board-certified music therapists.

After some contemplation about how to design the project, the writer decided to approach the Pathways Hospice Agency, a 501(c) not-for-profit organization operating in Oakland, California, with a four-month community outreach pilot study, from February 1, 2009, through May 31, 2009. The success of the project would be measured both quantitatively and qualitatively. The quantitative measurement would come from raising the percentage of Pathways' African American patients significantly above its level of 15%. The qualitative measurement would come from surveying relatives of the patients about their own and the patients' experience of the music therapy.

Abbreviated Literature Review

The writer begins the following section by defining music therapy and outlining a brief history of it, from its antecedents in ancient times to its professionalization in the 1940s. Then she reviews how music works as therapy, both in physiological and psychological terms. She concludes the section with a discussion of the economics of music therapy. Drawing on her decades of experience as a hospice care administrator, she has found ways to make music therapy cost-effective in that setting.

Section II: Review of the Evidence

The Definition and History of Music Therapy

Music therapy is not the simple playing of music—either live or recorded—to and for patients. According to the American Music Therapy Association (2005), music therapy is “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program” (¶ 1). Music therapy is a studied, learned, credentialed behavioral intervention. It is specific, prescribed, and delivered therapeutically. The body of its activity is evaluated and organized. Its knowledge is collected, reviewed, promoted, guarded, and delivered in accordance with defined principles (Hanser, 1985). In our scientific age, music therapy has been professionalized, with the first undergraduate degree issued in 1944 from Michigan State University, and the first graduate degree issued by the University of Kansas in the same year. Today, there are more than 70 institutions in the United States that provide baccalaureate, master’s, and doctoral degrees in music therapy. A board-certified music therapist has completed four years of university study, is competent in at least two instruments, has completed over two thousand hours of internship, and has passed a national certification exam.

Less formally, music has been used for therapeutic purposes for millennia. For example, there is a passage in the Old Testament that describes the future King David, still a boy, as a music therapist with his lyre for the ailing King Saul:

> Now the Spirit of the Lord departed from Saul, and an evil spirit from the Lord tormented him. And Saul’s servants said to him, “…Seek out a man who is skilful

> in playing the lyre; and when the evil spirit from God is upon you, he will play it, and you will be well….” And David came to Saul, and entered his service…. And whenever the evil spirit from God was upon Saul, David took the lyre and played it with his hand; so Saul was refreshed, and was well. (1 Samuel 16; 14–23)

Or as Confucius (ca. 500 B.C.) said, “Music produces a kind of pleasure which human nature cannot do without.”

In the 8th century A.D., in Persian and Egyptian institutions for the mentally ill, professional musicians, in addition to baths and drugs, were used to treat patients (Syed, 2007).

In the 9th century A.D., Abu Al-Nasr Al-Farabi (870–950 A.D.), the famous Turkistani Muslim philosopher and scientist, wrote that, “Music promotes good mood, moral education, emotional steadiness, and spiritual development. It is useful for physical health. When the soul is not in health, the body is also ill. Good music, which cures the soul, restores the body to good health” (quoted here from Alakbarov, 2003, p. 1).

Other examples of informal music therapy could be cited from different times and places. The point is that people have known for ages that music, as William Congreve (1697) said, “soothes the savage breast.”

How Music Works As Therapy

The Physiology of Music Therapy

We know from experience that music engages people’s attention, calms them down, and distracts them from their pain and suffering. But what is the physiological basis for this—for, as Myer (1956) noted, decades ago, psychological responses cannot be separated from physiological ones.

To begin with, it has been demonstrated that music can reduce heart rate and lower blood pressure in two ways: (a) by inhibiting the sympathetic adrenal circuit; and (b) by interfering with receptor response to dopamine, epinephrine, and norepinephrine, known as catecholamines (Hirokawa & Ohira, 2003; Knight & Richard, 2001; Sloboda, 1991; Takahashi & Matsushita, 2006).

Music can also increase the production of salivary immunoglobulin, which fights off bacterial infection in and inflammation of the mucosa of the bronchial, gastrointestinal, and urinary tracts (Hirokawa & Ohira, 2003; Knight & Richard, 2001; Kuhn, 2002).

Furthermore, music can stimulate an increase in two kinds of lymphocytes, both of which defend the body against tumor cells and virus-infected cells. Music *directly* stimulates the production of large granular lymphocytes, also known as natural killer cells. It *indirectly* stimulates the production of B-lymphocytes, first by increasing T-lymphocyte production, which in turn contributes to cytokine production, which then leads to the production of B-lymphocytes (Taylor,1997)

One of the great advantages of music is that it can affect people without the need to communicate with them logically via the cerebral cortex. In fact, music is received directly by the thalamus and sent on to the amygdala (Carlson, 1992; Taylor, 1997). Thus, music takes what LeDoux (2002) calls the “low road” through the limbic system, instead of the “high road” through the sensory cortex. This spares the individual the need to analyze and evaluate the stimuli. The therapeutic effect of this, insofar as hospice care is concerned, is that a music therapist can access patients’ previous rewards and pleasures, which are still retained despite disease, disability, and discomfort.

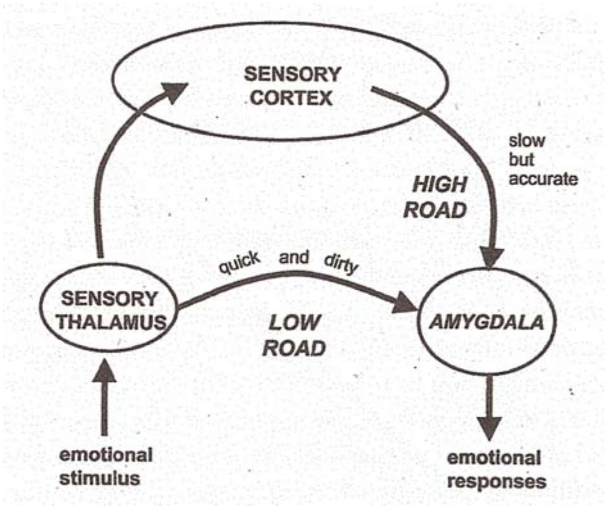

Figure 1: The "Low Road"
SOURCE: LeDoux (2002) p. 123

A minor benefit of music taking the "low road" is that it can cause chills to run up and down one's back, or what Huron (2007) calls "frisson," from the French word for "chills." This leads to piloerection, or the raising of the hair follicles, which allows the music therapist to observe, even in comatose patients, that the music is having an effect. Sloboda (1991) found that chills or shivers correlated with sudden changes of harmony or loudness. He also found that tears or a lump in the throat correlated with melodic appoggiaturas and sometimes harmonic sequences. Blood and Zatorre (2001) reported elevated activity in the thalamus and anterior cinguli, concurrent with the frisson phenomenon.

The Psychology of Music Therapy

The amygdala is a small almond-shaped cluster of neurons, deep in the temporal lobe, which has become recognized by neuroscientists as the seat of the emotions. It is located right next to the hippocampus, the current accepted specific brain tissue involved with memory. The amygdala appears to be involved in the integration of activities related to hormonal, behavioral, and autonomic stimuli, responses, and transmission. Although music can be responded to rationally by the cerebral cortex, it is the emotional responses, primarily by the integration function of the amygdala and the surrounding neurological structures, that can be used for therapeutic purposes (LeDoux, 2002; Restek, 2003).

Music can be a wonderful bridge from physiological to psychological responses. As Itzkoff (2005) noted, music is “probably the most paradigmatic searchlight into the relationship between our biological energies and their transformation into symbolic meaning” (p. 3).

If music is applied therapeutically in the hands of a knowledgeable practitioner, during or before a fearful or painful situation, the amygdala and the involved neurological structures can be conditioned to associate the experience with positive associations and decreased pain, while training the patient to avoid autonomic avoidance behaviors, such as “fight or flight” responses and their attendant hormonal secretions, such as adrenaline production (Hilliard, 2003; Taylor, 1997). In fact, there is no difference in this anxiolytic effect of music for either gender (Knight & Richard, 2001).

Music therapy can be effective not only in treating pain and anxiety, but also in counteracting depression and grief (Aldridge, 1995). Frampton (1986) recommended using all the arts to help people find meaning and purpose in what he called the “dying part of living.” Creative expression of any kind, noted Daykin, McClean, and Bunt (2007), can assist people to cope with loss, as well as with confused identity in the face of loss. Music can be especially effective in this connection. Dr. Mitchell Gaynor (2004), a prominent oncologist, stated that he has “never found anything more powerful than sound, voice, and music in allowing people to move to what I call ‘their own inner harmony, their own core, their own soul’” (p. 85), or what the present writer calls “reaching the person in the patient.” The whole point of music therapy for hospice patients, who have been “done to” and “done at” (Bradshaw, 1995), is to engage their emotional world to help them to live to the end.

Levitin (2007) sees an essential connection between music and memory. The latter, he says, “affects the music-listening experience so profoundly that it would not be hyperbole to say that without memory there would be no music” (pp. 166–167). Music therapy works the other way around, using music to stimulate memories. The present writer witnessed a profound instance of this with a hospice patient who was in her eighties. This particular woman was almost entirely nonverbal and withdrawn as she spent her final days coping with cancer, schizophrenia, and dementia. One day, when her daughter was present, a music therapist who was assigned to her came into the room and, at the suggestion of the daughter, began to sing “Amazing Grace,” accompanying herself on her guitar. Within seconds, the usually silent old woman began to sing along. At the end of the song, the daughter said, “I didn’t know you knew how to sing, Mama.” To which, the old woman replied, “There’s a lot you don’t know about your Mama.”

The connection between music and memory, Levitin argues, derives from the fact that music is based on repetition. “Music,” he says, “works because we remember the tones we have just heard and are relating them to the ones that are just now being played” (p. 167). Furthermore, memory is intimately related to our emotional system, both of which involve the amygdala. However, interestingly enough, whenever Levitin has conducted neuroimaging studies of the amygdala, he has found that it is invariably activated by music, but not by random sounds or musical tones.

The repetitive quality of music gives it a certain predictability. In fact, Taylor (1997) maintains that “musically activated neurophysiological responses are observable, measurable, and predictable, thus affording selection of music activities having predetermined positive effects on patients" (p. 34). What this means for music therapy is that music can be used in therapeutically predictable ways. For example, Spintge (1989), in a study of perioperative patients who received local and regional anesthetics, found that those individuals who also received music therapy had a measurable rise in their pain threshold, increased pain tolerance, and a 50% reduction in their usual dosage of sedative and analgesic drugs. This last point was confirmed in the context of hospice care by Romo and Gifford (2007), who similarly identified a significant decrease in the use of pharmacological agents among hospice patients who received music therapy, compared to those who did not.

Also in the specific context of hospice care, music therapy has been shown to decrease agitated behaviors in patients, help them to get along better with their family members (Lou, 2001; Sellick & Zaza, 1998), and improve their mood, affective awareness, motivation, and sense of control and self-esteem (Nayak, Wheeler, Shiflett, & Agostinelli, 2000; Ruud, 1997).

One would expect music therapy to be especially effective with the African American population because music has long been an essential construct of the African American community. Gospel, blues, jazz, soul, Dixieland, Motown, hip-hop, and rap all sing and play out the history of an oppressed minority asserting their authenticity as human beings. Music has enabled a resilience in African Americans that began hundreds of years ago and continues to be relevant to this day (Jackson & Tucker, 2008). Spirituality and church community, with ever-present song, are the root and the branch used by African Americans to address their concerns about life, death, oppression, and demoralization (Doka & Tucci, 2009, Burrs, Ervin, & Harper, 2004; Gerdner, Tripp-Reimer, & Simpson, 2007; Straw, 2003; Wlodarczyk, 2007).

The Economics of Music Therapy

Hilliard (2005), who surveyed hospice administrators about the desirability of incorporating music therapy into the care programs, discovered that the vast majority of them were interested in the idea, but argued that the current Medicare reimbursement structure does not pay for it, just as it does not pay for any of the other so-called complementary or alternative therapies.

However, the present writer has found two ways that music therapy in the context of hospice care can pay for itself: (a) if pharmacological usage decreases as the use of music therapists increases, as was just indicated above with the Romo and Gifford (2007) study, then costs go down accordingly; and (b) when music therapy is offered by hospice agencies, their enrollment goes up, which means their revenue increases.

Both of these points have been substantiated by the experience of the present writer, who has been actively engaged in the administration of hospice care for more than 20 years. For example, to illustrate the first point above, when this writer was the administrator of a hospice care agency in the San Francisco Bay Area, she was given approximately $200 per day per patient by Medicare. Of this, she had to spend an average of $10 per day per patient on pharmaceuticals. When she introduced music therapy into the program, the daily cost of the pharmaceuticals per patient went down to $6. At the same time, she paid the music therapist ($50 per hour for one hour per patient per week, which averaged a cost of $6.60 per day ($200/mnth divided by 30 days per month. Thus, a pharmaceutical cost savings of $28 per week ($4 per day) only cost her $ .88 cents per day. The increase revenue related to the market differentiator effect, covered this cost. Other cost savings occurred with decreased nursing visits for patients with music therapy.

As for the second point, during the three years that this writer was the administrator of the above hospice care agency, the average daily census (ADC) of patients increased from 10 to 125.

Without a doubt, her ability to offer music therapy as a component of the plan of care was the most significant market differentiator in building this census. Furthermore, when this writer worked as a marketing community outreach nurse for another hospice care agency, she similarly increased the ADC in four months from 75 to 93, largely thanks to offering music therapy.

Section III: Implementation Plan

Overview

The researcher recruited family members of African American hospice patients associated with a San Francisco Bay Area hospice care agency to evaluate the impact of music therapy on the quality of life of the hospice patients.

Pre-Study Demonstration Project

Prior to conceiving the qualitative component of the present study, this writer was working as the Community Liaison Outreach nurse for Pathways Hospice Agency, in Oakland, California, and came up with the idea that music therapy would be an excellent vehicle for recruiting African Americans to the hospice benefit. She then named this outreach project “Umoja,” from the first principle of Kwanzaa, which stands for unity and means to strive for unity in race, nation, community, and family (Karenga, 2009).

Next, she placed a notice on Craigslist, seeking music therapists who were board-certified by the American Association of Music Therapists, who would be willing to work for pay with hospice patients. Eight individuals responded to this notice, of whom, after interviews, the writer selected four. The writer then engaged these four individuals for four months, from February 1, 2009, through May 31, 2009.

With the music therapists in place and Pathways’ approval to proceed assured, the writer then informed referral sources throughout the East Bay area about this unique outreach to an underserved minority population. The referral sources included hospital case managers and social workers, doctors and nurses, and staff members at clinics and nursing homes. These individuals warmly welcomed the strategy, since their experience had been that African Americans tend to decline hospice care. Ultimately, the music therapy program worked so well at Pathways that this writer decided to construct an academic project around it, which led to the present study.

Participants

The 10 participants in the qualitative part of this study were relatives of recently deceased African American hospice patients at Pathways, who had received music therapy through the agency as part of the Umoja Project.

Instruments

Four instruments were used in this study: (a) an application to the University of San Francisco’s Institutional Review Board (IRB) for the Protection of Human Subjects, requesting permission to conduct the study (see Appendix A); (b) a consent form to be signed by the participants (part of Appendix A); (c) a written survey to be filled out by the participants (part of Appendix A); and (d) an interview with the participants (see Appendix B).

The written survey asked the participants to evaluate the following 10 statements, using a 5-point Likert scale (1 = Strongly Disagree; 2 = Disagree; 3 = Neutral; 4 = Agree; 5 = Strongly Agree):

1. Board-certified music therapy enhanced the life experience.
2. The personal, active presence of a board-certified music therapist enhanced the experience of the music more than mechanically played music.
3. Board-certified music therapy should be available to all hospice patients and families.

4. The use of board-certified music therapy would influence my recommendation to others to use Pathways Hospice Agency.
5. The board-certified music therapy assisted the connection of family to patient.
6. The board-certified music therapy increased pleasant reminiscence.
7. The board-certified music therapy added a personal dimension not available through other disciplines.
8. The board-certified music therapist's services were *not* beneficial.
9. The board-certified music therapist benefited the family more than the patient.
10. The board-certified music therapist benefited the patient more than the family.

The interview, which lasted for half an hour, was unstructured and open-ended, but contained three basic questions:

1. How did the music therapy affect the quality of life for the patient and the family?
2. How did the music therapy affect the quality of death for the patient and the family?
3. Would you recommend hospice care with music therapy versus hospice care without music therapy, and why?

Procedures

After receiving permission from the IRB to proceed with the study, the researcher obtained 10 participants in the following way. At the onset of the study, Pathways had 33 African American patients, 23 of whom had chosen to have music therapy. The researcher wrote to the primary relative of each of these 23 patients, asking if that person would like to participate in a study evaluating the efficacy of music therapy in the context of hospice care. Eventually, 10 relatives formally agreed to participate in the study by signing a consent form.

The researcher met in person at the homes of the seven participants who resided in the San Francisco Bay Area, and talked with the other three by phone. In all 10 cases, the session began with the family member answering the 10 survey questions. The in-person participants filled out a written questionnaire, and the researcher filled out the same form for the three participants who spoke to her by phone. This part of the session lasted approximately five minutes for all of the parties.

The remaining 25 minutes of the sessions were devoted to the interviews. These began with the researcher asking if the participants would agree to having the interview tape-recorded. Three of them agreed to this, and seven declined. With her three basic questions in front of her, typed on a piece of paper, the researcher began all 10 interviews by asking the first question: “How did the music therapy affect the quality of life for the patient and the family?” In the course of the conversations, the researcher asked the other two questions in any order that seemed appropriate and comfortable for the participants.

When the 10 interviews were completed, the researcher transcribed the three recorded interviews (see Appendix B), using fictitious names to protect the confidentiality of the participants.

Expected Outcomes

The writer expected the participants to be positive about music therapy in the context of hospice care, but she did not know *how* positive they would be, nor did she know specifically what they would say.

Section IV: Evaluation

Impact on Patient Outcomes

Increasing the Percentage of African American Patients in Hospice Care

The Umoja Project worked exceedingly well. That is, the utilization of board-certified music therapists drew significant numbers of African American patients into hospice care. In fact, the researcher's desire to increase the percentage of African American patients at Pathways by five percentage points—namely, from 15% to 20%—was actually exceeded. By the end of the project's four-month trial, the percentage of African American patients at Pathways was 25%—an increase of 10 percentage points.

Furthermore, when this pilot project came to an end, and music therapy was no longer offered as part of the care plan, the percentage of African Americans at Pathways returned to 17%. Clearly, since no other strategy to attract African Americans to Pathways was employed during this period, it must have been the option of music therapy that made the difference.

By implementing this strategy, Pathways not only increased the numbers of its patients, but also the size of its revenues. Prior to the implementation of the Umoja Project, the average daily census (ADC) at Pathways was 75 patients. At the conclusion of the project, the ADC was 93. The accepted method of projecting revenue in the hospice industry is to multiply number of patient days by average length of stay (ALOS). During the four months of the Umoja Project, the ALOS was 51.98 days. Thus, the number of patient days increased from 3,899 to 4,834:

75 x 51.98 = 3,899

93 x 51.98 = 4,834

The intervention therefore yielded 935 additional patient days:

4,834 – 3,899 = 935

At approximately $200 per day of Medicare payments, additional revenue of $187,000 was generated over the four-month period:

935 x $200 = $187,000

On an annual basis, this would have generated more than half a million dollars of additional revenue:

$187,000 x 3 = $561,000

Evaluating the Interviews

Four primary themes emerged from the interviews: (a) the music therapy gave the patients something to look forward to; (b) the music therapy gave the family members insights into the patient's current mood; (c) the music therapy helped the family members to learn things about the patient that they did not previously know; and (d) live music was far preferred to taped music.

Something to Look Forward to. Of the 10 relatives whom the researcher interviewed, six voluntarily reported that their patient-relative had “looked forward to” the music therapy sessions with great enthusiasm. The other four relatives reported the same thing when they were asked about their relative’s response.

A daughter of one of the patients told this researcher that her father had not had a whole lot to look forward to in the last year of his life. In fact, before the music therapy, she said, family dinners, especially when the grandchildren came, were the only thing that gave him any pleasure at all. Once the music therapist came into the picture, the patient took great joy in having the therapist sing Broadway show tunes to him, sometimes accompanying her on a drum that she provided. Later, when his physical condition worsened, the patient asked the therapist to sing hymns that he had sung as a boy in church with his family, and that, as a parent, he had sung in church with his own children. Incidentally, all the music therapists played a guitar and a keyboard instrument, which they did not pass around, and also allowed the patients to play small drums, a triangle, and maracas, which, for infection control, are easy to wipe down hygienically between uses.

In another example of a patient having something to look forward to, the surviving husband told this researcher that he and his wife had often sung together in past year, but she had been too weak to accompany him during the hospice experience. However, she had loved to listen to him sing along with the music therapist. In fact, he soon brought in songs to sing that he had himself composed years before for his wife. One of these was entitled “Lord, Don’t Let Me Walk This Road Alone.” These weekly sessions brought great pleasure to the patient, who, when talking to her family, would refer to the therapist as “my musician.” This was true of two other patients as well.

Having something to look forward to at a time when almost everything of importance to the patient has been lost is a powerful recommendation for this type of therapy. Being able to feel that something is “mine” helps the patients to live right up to the end.

Insights into the Patient’s Current Mood. Since the music, or at least the genre of music, played by the therapist was usually chosen by the patient, these choices revealed something about the patient’s emotional state at the time. The family members were present at 32 of the 79 Umoja sessions that occurred during the four-month trial, so these individuals were able to report that they felt the patients were choosing music specifically to communicate messages to them that were too difficult for the patients to convey conversationally. According to these reports, two pieces were chosen more than any other: the church hymn “Amazing Grace” and Frank Sinatra’s song “My Way.” The first of these contains a somewhat apologetic message, whereas the second is more self-assertive:

“Amazing Grace”

Amazing Grace, how sweet the sound,
That saved a wretch like me….
I once was lost but now am found,
Was blind, but now, I see.

T’was Grace that taught…
my heart to fear.
And Grace, my fears relieved.
How precious did that Grace appear…
the hour I first believed.

Through many dangers, toils and snares…
we have already come.
T’was Grace that brought us safe thus far…
and Grace will lead us home.

The Lord has promised good to me…
His word my hope secures.

He will my shield and portion be…
as long as life endures.

When we've been here ten thousand years…
bright shining as the sun.
We've no less days to sing God's praise…
than when we've first begun.

Amazing Grace, how sweet the sound,
That saved a wretch like me….
I once was lost but now am found,
Was blind, but now, I see. (John Newton, 1725–1807)

"My Way"

And now the end is near
And so I face the final curtain
My friend I'll say it clear
I'll state my case of which I'm certain
I've lived a life that's full
I traveled each and every highway
And more, much more than this
I did it my way (Anka, 1967)

Learned Things About the Patient. As was noted above in the physiological and psychological discussion of music, it often has associations in people's minds with specific events or experiences in their past. Thus, hearing a piece of music can trigger memories. In the case of the hospice patients, this triggering often led to them revealing aspects of their personal history that their relatives were not familiar with. All 10 interviewees in this study reported this phenomenon, adding that they could not think of any other way that this could have been accomplished.

Preference for Live Music. All 10 family members expressed the opinion, in one way or another, that the personal touch involved in having a musician right in the room with the patient was far more therapeutic than canned music would have been.

Evaluating the Written Surveys

The written surveys essentially confirmed in more quantitative terms what the relatives stated orally in the interviews. On a 5-point Likert scale (1 = Strongly Disagree; 2 = Disagree; 3 = Neutral; 4 = Agree; 5 = Strongly Agree), the results for the 10 questions were as follows.

Question 1: Board-certified music therapy enhanced the life experience. Nine of the participants strongly agreed with this statement, and one agreed.

Question 2: The personal, active presence of a board-certified music therapist enhanced the experience of the music more than mechanically played music. Eight of the participants strongly agreed with this statement, one agreed, and one was neutral.

Question 3: Board-certified music therapy should be available to all hospice patients and families. All 10 of the participants strongly agreed with this statement.

Question 4: The use of board-certified music therapy would influence my recommendation to others to use Pathways Hospice. Nine of the participants strongly agreed with this statement, and one agreed.

Question 5: The board-certified music therapy assisted the connection of the family to the patient. Seven of the participants strongly agreed with this statement, two agreed, and one was neutral.

Question 6: The board-certified music therapy increased pleasant reminiscence. Eight of the participants strongly agreed with this statement, one agreed, and one was neutral.

Question 7: The board-certified music therapy added a personal dimension not available through other disciplines. Eight of the participants strongly agreed with this statement, and two agreed.

Question 8: The board-certified music therapists' services were NOT beneficial. All 10 of the participants strongly disagreed with this statement.

Question 9: The board-certified music therapist benefited the family more than the patient. Five of the participants strongly agreed with this statement, two agreed, and two were neutral, and one strongly disagreed.

Question 10: The board-certified music therapist benefited the patient more than the family. Eight of the participants strongly agreed with this statement, and two agreed.

The only confusion in these responses appears in the apparent contradiction between the answers to questions 9 and 10. To be totally consistent, the eight individuals who strongly agreed that the therapy benefited the patient more than the family should have strongly disagreed that the therapy benefited the family more than the patient. And the same logic should have applied to the other two family members who agreed that the therapy benefited the patient more than the family. The researcher can only conclude from the actual responses that many of the family members misread question 9.

Impact on the Health-Care Environment

As was just demonstrated, the patients and their relatives were highly satisfied with music therapy's ability to enhance the end-of-life experience. Furthermore, as was demonstrated earlier, as the amount of music therapy goes up, the cost of medications goes down. Also, thanks to increased enrollments, the revenues go up. In addition, as Romo and Gifford (2007) demonstrated, the use of music therapy leads to fewer visits by nurses, thus further reducing costs to the hospice agencies. Precisely why nursing visits decrease when music therapy is part of the plan of care has never been determined, and could well become the subject of a formal study in the future.

Finally, in the facts and figures recently published by the National Hospice and Palliative Care Organization (2009), it was reported that 75.4% of family members rated hospice care as “Excellent.” This means that nearly one in four relatives rated hospice care as less than excellent. In the survey and interviews conducted by the present writer, 100% of the family members agreed that board-certified music therapy should be available to all hospice patients and families. Thus, it is this writer’s contention that the way to raise family satisfaction to a level of 100% “Excellent” would be to introduce music therapy into all the hospice programs throughout the nation.

Section V: Continuous Quality Improvement Process

Feasibility and Cost-Effectiveness

Given the cost-effectiveness of music therapy and its positive reception by both patients and their families, making music therapy an integral part of all hospice care programs is totally feasible.

Intraprofessional Impact

When it becomes widely known in the nursing profession, thanks to studies like the present one, how effective and desirable music therapy is as a component of hospice care, nurse-leaders will embrace it on an ever wider scale. In the meantime, it would be useful to conduct studies of field nurses’ responses to music therapy in the hospice context.

Section VI: Implications for Advanced Nursing Practice or Systems Leadership

Summary of Process

In a nutshell, nursing administrators must first recognize the value of music therapy as an adjunct to nursing care in the hospice setting. Once they realize how effective music therapy is, both physically and psychologically, as has been demonstrated by numerous scientific studies, nursing administrators will have little difficulty finding highly trained music therapists with whom to collaborate. Once the music therapists are in place, the process tends to run fairly spontaneously, with the patients selecting the music they want to hear, and the therapists providing it.

Lessons Learned

Before conducting this research, the writer had a hunch that music somehow reaches the "person in the patient" in a way that nothing else in hospice care can match. From the neuroscientific literature, especially the writings of Joseph LeDoux (1996, 1999, 2002), she learned that music beats a path straight to the amygdala, taking the so-called "low road," without the intercession of the cerebral cortex. This helps to explain the impact of music even on seriously demented patients.

From the interviews and the surveys the researcher conducted for this study, she learned two primary lessons: (a) how enthusiastically the patients looked forward to the visits of the music therapist; and (b) how much the family learned about their relative in hospice care as a direct response of the patient to the music therapy.

Dissemination Plan

The positive results of the Umoja Project and the recommendations made here for further study will be submitted, in the form of articles, to journals devoted to hospice and palliative care, nursing innovations, the cost-effective use of medical resources, and music therapy. The writer will also present her findings and recommendations in speeches and presentations to professional, religious, political, academic, and business organizations.

Although the writer would like music therapy to be included in hospice care programs for all populations, she is especially dedicated to finding ways to using music therapy to make hospice care more attractive to African Americans.

References

Abdullah v. Pfizer Inc. (2003). No. 02–9223, 2nd Cir. 10/08/2003.

Alakbarov, F. (2003). Music therapy: What doctors knew centuries ago. *Azerbaijan International* Autumn, *11*(3), 1–3.

Aldridge, D. (1995). Spirituality, hope, and music therapy in palliative care. *The Arts in Psychotherapy*, *22*(2), 103–109.

Aldridge, D. (1998). Life as jazz: Hope, meaning, and music therapy in treatment of life-threatening illness. *Advances in Mind-Body Medicine*, *14*, 211–282.

Allscripts Home Care. (2009). Version 5.0.1 as licensed to Pathways HomeHealth, Hospice and Private Duty. Pathways East Bay Demographics Report. Retrieved on July 1, 2009.

American Association of Colleges of Nursing (AACN). (2004). *DNP position statement*. Retrieved on August 1, 2009, from http://www.aacn.nche.edu/DNP/DNPPositionStatement.htm/

American Hospital Association. (2005) *Covenant of churches: Saint Barnabas Hospice and Palliative Care Center*. Retrieved on October 17, 2009, from http://www.aha.org/aha/news-center/awards/circle-of-life/awardees.html/

American Music Therapy Association. (2009). *Quotes about music therapy*. Retrieved on October 29, 2009, from http://www.musictherapy.org/quotes.html/

Angelou, M. (1978). *And still I rise*. New York: Random House.

Anka, P. (1967). Lyrics to “My way” (song). Retrieved on June 6, 2009, from http://www.elyrics. net/read/f/frank-sinatra-lyrics/my-way-lyrics.html/

Athar, S. (2007). *Medical ethics: An Islamic perspective*. Retrieved on October 16, 2007, from http://www.islam–usa. com/e2.html/

Blood, A. J., & Zatorre, R. J. (2001). Intensely pleasurable responses to music correlate with activity in brain regions implicated in reward and emotion. *Proceedings of the National Academy of Sciences, 98*(11), 818–823.

Born, W., Greiner, K. A., Butler, J., & Ahluwalia, J. S. (2004). Knowledge, attitudes, beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine, 7*, 247–256.

Bradshaw, A. (1995). What are nurses doing to patients? A review of theories of nursing, past and present. *Journal of Clinical Nursing*, 4, 81–92.

Buerhaus, P. I. (2007). Hopes and threats for nursing’s future: An interview. *Nursing Economic$, 25*(3), 183–185.

Burrs, F. A., Ervin, M. G., & Harper, B. C. (2006). *The future of hospice care for African Americans: Clinical, policy, and caregiver perspectives*. Retrieved on August 19, 2008, from http://www.iceol.duke. edu/respurces/lastmiles/papers/08.html/

Byock, I. (1997). *Dying well.* New York: Berkeley Publishing Group.

Canter, P. H., Coon, J. T., & Ernst, E. (2006, December). Cost-effectiveness of complementary therapies in the United Kingdom—A systematic review. *Evidence-Based Complementary Alternative Medicine, 3*(4), 425–432.

Carlson, N. R. (1996). *Foundations of Physiological Psychology.* Boston: Allyn & Bacon.

Cepeda, M. S., Carr, D. B., Lau, J., & Alvarez, H. (2006). Music for pain relief. *Cochrane Database of Systematic Reviews,* Issue 2, Article Number CD004843. DOI:10.1002/ 14651858. CD004843. pub 2.

Chiappelli, F., Prolo, P., Rosenblum, M., Edgerton, M., & Cajulis, O. S. (2006, March). Evidence-based research in complementary and alternative medicine, II: The process of evidence-based research. *Evidence-Based Complementary Alternative Medicine, 3*(1), 3–12.

Chochinov, H. M. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *Cancer Journal for Clinicians, 56,* 84–103.

Cody. (2007). *Theory of human becoming: A brief introduction*. Retrieved on November 12, 2007, from http://www.humanbecoming.org/site/theory.html/

Confucius. (ca. 500 B.C.). *The book of rites*, chap. 17. In H. L. Mencken (Ed.), (1966), *A new dictionary of quotations on historical principles from ancient and modern sources*. New York: Knopf.

Congreve, W. (1697). *The mourning bride*. In H. L. Mencken, (Ed.), (1966), *A new dictionary of quotations on historical principles from ancient and modern sources*. New York: Knopf.

Connor, S. R., Elwert, F., Spence, C. & Christakis, N. A. (2008). Racial disparity in hospice use in the United States in 2002. *Palliative Medicine, 22,* 205–213.

Craig, J. V., & Smyth, R. L. (2007). *The evidence-based practice manual for nurses,* 2nd ed. Philadelphia: Churchill Livingstone, Elsevier.

Daykin, N., McClean, S., & Bunt, L. (2007). Creativity, identity, and healing: Participants' accounts of music therapy in cancer care. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine*, *11*(3), 349–370.

DeMarco, R. (2009). *Doctorate in nursing practice: A survey of Massachusetts nurses*. Retrieved on June 2, 2009, from http://www.sciencedirect.com. ignacio.usfca.edu/science?www. sciencedirect.com.ignacio.usfca.edu/science?_ob=articleURL&_udi=B6WK/

Doka, K. J., & Tucci, A. S. (Eds.). (2009). *Living with grief: Diversity and end-of-life care.* Washington, DC: Hospice Foundation of America.

Evans, D. (2001). Evidence-based practices information sheet for professionals: Music as an intervention in hospitals. *Best Practices of Joanna Briggs Institute for Evidence-Based Nursing and Midwifery*, *5*(4) 1–6.

Fife, R. B. (2009). Diversity and access to hospice care. In K. Doka & A. S. Tucci (Eds.), *Diversity and end-of-life care* (pp. 49–62). Washington, DC: Hospice Foundation of America.

Frampton, D. (1986, December 20–27). Restoring creativity to the dying patient. *British Medical Journal*, *293*, 1593–95.

Franklin, M. D., Schlundt, D. G., & Walleston, K. A. (2008). Development and validation of a religious health fatalism measure for the African American faith community. *Journal of Health Psychology*, *13*(3), 323–335.

Gaston, E. T. (1964). The aesthetic experience and biological man. *Journal of Music Therapy*, *1*, 1–7.

Gaynor, M. (2004). One oncologist's view of integrative care. Keynote address at the Comprehensive Cancer Conference, April 2003. *Integrative Cancer Therapies*, *3*(1), 82–87.

Gerdner, L. A., Tripp-Reimer, T., & Simpson, H. C. (2007). Hard lives, God's help, and struggling through: Caregiving in the Arkansas Delta. *Journal of Cross Cultural Gerontology*, *22*, 355–374.

Grewe, O., Nagel, F., Kopiez, R., & Altenmüller, E. (2007, February). *Listening to music as a re-creative process: Physiological, psychological, and psychoacoustical correlates of chills and strong emotions*. Retrieved on November 7, 2009, from http://0–proquest.umi.com.ignacio. usfca.edu/pqdweb?index=2&sid…pe=PQD&rqt=30&TS=1257616340&clientid=16131&cc=1&TS=1257616340/

Groen, K. M. (2007). Pain assessment and management in end-of-life care: A survey of assessment and treatment practices of hospice music therapy and nursing professionals. *Journal of Music Therapy*, *44*(2), 90–112.

Hanser, S. B. (1985). Music therapy and stress reduction research. *Journal of Music Therapy*, *22*, 193–206.

Hathaway, D., Jacob, S., Stegbauer, C., Thompson, C., & Graff, C. (2006). The practice doctorate: Perspectives of early adopters. *Journal of Nursing Education*, *45*, 487–496.

Hawkins, R., & Nezat, G. (2009). *Doctoral education: Which degree to pursue?* Retrieved on June 30, 2009, from http://www.aana.com/aanajournal.aspx/

Hilliard, R. E. (2003). The effects of music therapy on the quality and length of life of people diagnosed with terminal cancer. *Journal of Music Therapy, 40*(2), 113–137.

Hilliard, R. E. (2005, June). Music therapy in hospice and palliative care: A review of the empirical data. *Evidence-based complementary alternative medicine*, *2*(2), 173–178.

Hirokawa, E., & Ohira, H. (2003). The effects of music listening after stressful tasks on immune functions, neuroendocrine responses. and emotional states in college students. *Journal of Music Therapy*, *40*(3), 189–211.

Horne-Thompson, A., Daveson, B., & Hogan, B. (2007). A project investigating music therapy referral trends within palliative care: An Australian perspective. *Journal of Music Therapy*, *44*(2), 139–155.

Hospital Council of Northern and Central California. (2007, August). Select health indicators for cities in Alameda County, 2007. The Alameda County Public Health department, Office of the Director Community Assessment, Planning, and Education (CAPE) Unit. Oakland, CA: Alameda Public Health Department.

Huron, D. (2007). *Sweet anticipation: Music and the psychology of expectation.* Cambridge, MA: MIT Press.

Itzkoff, S. W. (2005, Fall). Art, intelligence, and the limbic system. *Mankind Quarterly*, *46*(1), 99–115.

Jackson, F. (2008). *African American perspectives on pain and palliative care*. Retrieved on May, 16, 2008, from http://www.iceol.duke.edu/resources/lastmiles/papers/02.html/

Jackson, T. A., & Tucker, M. (2008, June 29). *Jazz: Grove music online*. Retrieved on June 29, 2008, from http://o-www.oxfordaass.com.ignacio. usfca.edu/article/grove/795144?hi=04 highlight=IE/

James, G. O. (2009, November 2). *Our lord will be our strength through all of life.* Homily at Beth Eden Church, Oakland, CA.

Johnson, K. S., Kuchibhatla, M., Tanis, D., & Tulsky, J. A. (2007). Racial differences in growth of non-cancer diagnoses among hospice enrollees. *Journal of Pain and Symptom Management*, *34*(3), 286–293.

Johnson, K. S., Kuchibhatla, M., Tanis, D., and Tulsky, J. A., (2008). Racial differences in hospice revocation to pursue aggressive care. *Archives of Internal Medicine, 168*(20), 218–224.

Johnson, K. S., Kuchibhatala, M., Sloane, R. J., Tanis, D., Galanos, A. N., & Tulsky, J. A. (2005). Ethnic differences in the place of death of elderly hospice enrollees. *Journal of American Geriatric Society*, *53*, 2209–15.

Jones, J. D. (2006). The use of control groups in music therapy research: A content analysis of articles in the *Journal of Music Therapy*. *Journal of Music Therapy, 43*(4), 334–355.

Kuhn, D. (2002). The effects of active and passive participation in musical activity on the immune system as measured by salivary immunoglobulin A (SigA). *Journal of Music Therapy*, *39*(1), 30–39.

Latson, S. R., & Ramsey, G. (2004). Advanced care planning: An overview. In *Topics on end-of-life care* (conference monograph). Washington, DC: Care for African Americans National Conference.

LeDoux, J. (1996). *The emotional brain.* New York: Simon & Schuster.

LeDoux, J. (1999). The power of emotions. In R. Conlan (Ed.), *States of mind: New discoveries about how our brains make us who we are* (pp. 123–149). New York: John Wiley.

LeDoux, J. (2002). *Synaptic self: How our brains become who we are.* New York: Penguin.

Levitin, D. J. (2006). *This is your brain on music: The science of a human obsession*. New York: Penguin.

Lou, M. F. (2001). The use of music to decrease agitated behaviour of the demented elderly: The state of the science. *Scandinavian Journal of Caring Science, 15*, 165–173.

Mackay, T. (2008). Practice value and worth of a DNP. *Clinical Scholars Review, 2*(1), 8–9.

Miller, A. (2008, May/June). Issues related to utilization of health care at end of life. *Medicare Patient Management*, pp. 27–30.

National Hospice and Palliative Care Organization (NHPCO). (2007). *Facts and figures: Hospice care in America*. Retrieved on October 30, 2009, from http://www. nhpco.org/nds/

National Hospice and Palliative Care Organization (NHPCO). (2008). *Facts and figures: Hospice care in America*. Retrieved on October 10, 2008, from http://www. nhpco.org/nds/

National Hospice and Palliative Care Organization (NHPCO). (2009). *Facts and figures: Hospice care in America*. Retrieved on November 12, 2008, from http://www. nhpco.org/nds/

Nayak, S., Wheeler, B. L., Shiflett, S. C., & Agostinelli, S. (2000). Effect of music therapy on the mood and social interaction among individuals with acute traumatic brain injury and stroke. *Rehabilitation Psychology*, *45*(3), 274–283.

Newton, J. (1725–1807). *Amazing grace* (hymn). Retrieved on July 5, 2009, from http://www.constitution.org/col/amazing_grace.htm/

Omonzejele, P. F. (2008, March/April). African concept of health, disease, and treatment: An ethical inquiry. *Explore*, *4*(2), 120–126.

Office of Statewide Health Planning and Development (OSHPD). (2008). *Data alerts*. Retrieved on July 1, 2009 from https://www.alerts.oshpd.ca.gov/crudutilreport.spx?pmode=2&psd=35267&pfid=4872/

Payne, R. (2006). *Team customizes and pilots end-of-life curriculum for African American health-care professionals.* Retrieved on July 28, 2009, from http://www.rwjf.org/pr/product.jsp?id=16763/

Phipps, E., True, G., & Harris, D. (2003). Approaching the end of life: Attributes, preferences of African Americans working with white patients and their family caregivers. *Journal of Clinical Oncology*, *21*, 549–554.

Pietroburgo, J. (2004). Joining forces, joining futures: Hospice at the crossroads. *American Journal of Hospice & Palliative Care*, *21*(3), 209–215.

Pilkington, F. B., & Lee, O. J. (1999). Practice with persons living their dying. A human becoming perspective. *Nursing Science Quarterly*, *12*(4), 324–328.

Prion, S. (2009, September 24). *MS generalist to DNP: Emphasis—Healthcare systems leadership*. Retrieved on November 11, 2009, from http://www.usfca.edu/nursing/programs_of_study/dnp_program_for_msn_hcsl.html/

Restek, R. (2003). *The new brain: How the modern age is rewiring your mind*. Gordonsville, VA: Holtzbrinck publishers.

Romo, R., & Gifford, L. (2007). A cost benefit analysis of music therapy in a home hospice. *Nursing Economic$*, *25*(6), 353–358.

Ruud, E. (1997). Music and the quality of life. *Nordic Journal of Music Therapy, 6(2),* 86–97.

Schira, M. (2007). Leadership: A peak and perk of professional development. *Nephrology Nursing Journal*, *34*(3), 289–294.

Searight, R. H., & Gaffrod, J. (2005). *Cultural diversity at the end of life: Issues and guidelines for family physicians*. Retrieved on July 12, 2008, from http://www.aafp.org/afp/20050201/515. html/

Sellick, S. M., & Zaza, C. (1998). Critical review of five nonpharmacological strategies for managing cancer pain. *Cancer Prevention & Control*, *2*(1), 7–14.

Sloboda, J. A. (1991). Music structure and emotional response: Some empirical findings. *Psychology of Music*, *19*(2), 110–120.

Spintge, R. K. W. (1989). The anxiolytic effects of music. In M. H. M. Lee (Ed.), *Rehabilitation, music, and human well-being* (pp. 82–97). St. Louis: MMB Music.

Straw, G., & Cummins, R. (2003). American Association of Retired Persons North Carolina end-of-life care survey: Knowledge management. In T*opics on end-of-life care* (conference monograph). Washington, DC: Care for African Americans National Conference.

Syed, I. B. (2007). *Music therapy*. Retrieved on October 16, 2007, from http://www.IRFI.org/ articles/

Takahashi, T., & Matsushita, H. (2006). Long-term effects of music therapy on elderly with moderate/severe dementia. *Journal of Music Therapy*, *43*(4), 317–333.

Taylor, D. B. (1997). *Biomedical foundations of music as therapy*. St. Louis: MMB Music.

Turner, J. (2004). *Music therapy, description, origins*. Retrieved on October 16, 2007, from http://www.vhi.ie/topic100587171/

U.S. Census Bureau. (2009). *Fact sheet*. Retrieved on July 5, 2009, from http://factfinder.census. gov/servjet/acssafffacts?_event=search&geo_id=0500045060001&_gescontext=0100045%7 c04000/

Vink, A. C., Birks, J. S., Bruinama, M. S., & Scholten, R. J. P. M. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews,* Issue 4, Article Number CD003477.DOI:10.1002/14651858.CD003477.pub2.

Wlodarczyk, N. (2007). The effect of music therapy on the spirituality of persons in an in-patient hospice unit as measured by self-report. *Journal of Music Therapy*, *44*(2), 113–122.

Zahovaeva, A. (2007). Art as philosophy of healing. *The Philosopher*, *93(*1), 7.

Appendices

Appendix A: IRB Approval Form

IRBPHS INITIAL APPLICATION

Name of Applicant: Elizabeth Joy “Lisa “ Gifford
USF ID #: 11311493
School: USF School of Nursing
Department: DNP Health Systems Leadership
Home address: “Oak Perch”
748 B Street
Hayward, Ca 94541
Home phone: 510-881-2939
Work phone: 510-385-3515
Cell phone: 408-834-3484
Email: Lgiffman1@aol.com
Other Investigators: 0
Faculty Advisor: Marjorie Barter RN EdD
Professor Health Systems Leadership, DNP
Campus address: Cowell School of Nursing
Email: Barterm@usfca.edu
Date: June 15, 2009

Project Title: The UMOJA Project: Use of board certified music therapy as a tool to minimize disparities, and encouraging utilization of hospice care by African Americans.

1. Background and Rationale

Pathways Hospice Foundation, a 501(c) not for profit organization operating in the San Francisco Bay Area, exists to ensure that all who need hospice care can be served. The recognized problem is under utilization of the Hospice benefit by African Americans (AA). AA persons represent 8% of hospice enrollees according to the National Hospice and Palliative Care Organization (NHPCO,2007). African Americans represent 13% of the total population in the United States (U.S. Census Bureau 2008). In the San Francisco Bay Area, among all Medicare certified hospice submit data to the state, 2007 reports indicate that only 2% of all the hospice participants are AA (OSHPD 2008). In the Oakland Bay Area there is a 35% AA population and the Pathways East Bay agency serving the same area that reports 15% of their census is AA patients (Allscripts 2009). AA have a significantly higher revocation of the hospice program even when they are enrolled. In the Pathways East Bay office 20% of persons revoking are AA (Allscripts 2009). Themes of mistrust and cultural fatalism are significant obstacles to utilization of hospice (Franklin, Schlundt & Wallston, 2008). The mistrust is tied to a legacy of slavery, abuses in medical experimentation, and economic injustices real and perceived. Without hospice, terminally ill patients are less likely to have pain and symptom management, psychosocial support, nursing care and bereavement support...all provided by the Hospice interdisciplinary team. (Johnson, Kuchibhatla, Tanis & Tulsky, 2007). Therefore, The Umoja project will build trust, increase awareness and improve the health of AA patients.

“Umoja” from the first principle of Kwanzaa stands for unity and means “to strive for and maintain unity in family, community, nation and race (Karenga 2009). The Umoja Project proposes two strategies: outreach to church communities and board certified music therapy to meet the needs of dying AA patients/families. The Umoja project recognizes the deep connection of music in the AA population. The Umoja project honors and recognizes the importance of music to the health of AA communities. The Umoja project develops essential connection based on recognition of value in the AA culture itself, instead of viewing the population as a group in process of assimilating into the dominant culture. Umoja will work within the community of a unique religious and spiritual culture to: (1) reduce distrust, (2) improve hospice utilization. As scientific understanding of neuronal circuitry develops, it is imperative that professional nursing strive to understand and activate complementary integrative therapies that reduce suffering, meet professional criteria, collaborate with other disciplines, and further honor humanity in all of its splendor and complexity.

> “We gave them seeds, they gave us cotton. We gave them sorrow, they gave us song!”
>
> --from a Sunday sermon of Dr. Gillette O. James, Beth Eden Church, Oakland, CA

2. **Description of Sample**

a. The subject sample consists of persons self identified as African American, who were patients and patient families of Pathways East Bay Hospice during the days from February 1, 2009 thru May 31, 2009, who were offered Board Certified Music Therapy, adjunctive to their Hospice plan of care. Of the total 33 subjects who met criteria, 23 subjects were able or chose to use the intervention, all over the age of 65, and all utilizing their Medicare Hospice benefit or MediCal Hospice benefit. Some subjects were utilizing their Medical Long Term Care benefit in addition to the Hospice benefit; i.e., MediCal was covering room and board in a skilled nursing facility (SNF). All subjects had Certification of Terminal illness by two physicians, the primary care physician and the medical director of Pathways Hospice.

b. The subjects with terminal conditions voluntarily chose the hospice benefit and signed consents for treatment. The Umoja opportunity was presented as a pilot project that was being offered at no cost to them or the agency. The Board Certified Music Therapists were engaged after they completed the Pathways Volunteer Process and administered the intervention, with relevant documentation, as volunteer notes, meeting the requirements of Medicare Conditions of Participation. The researcher intends to contact patients/families who utilized the intervention. The contact will be made by phone or letter requesting their participation in the qualitative 30 minute interview, in which participants will be asked the following questions: 1) How did the music therapy affect quality of life for the patient and family 2) How did the music therapy affect quality of death for the patient and the family and 3) Would you recommend hospice care with music therapy versus hospice care without music therapy, and why. A letter of Pathways support for this research accompanies this IRB Initial Application. The researchers letter to the potential interviewees also accompanies this application.

c. The patients are all voluntary participants in the Umoja Project free music therapy program through Pathways.

3. **Recruitment Procedure**

a. The researcher intends to gain access to subjects, through first calling families and patients, mailing letters, then arranging a meeting in person to obtain informed consent for interviews. If patients are alive, their current hospice case manager will present them with the informed consent form and request their participation.

b. Three attempts at contact will be made with potential participants through 1 letter and 2 phone calls.

c. Recruitment materials include: A cover letter and letter of informed consent (included).

4. **Subject Consent Process**

b. The procedure for obtaining informed consent will be a meeting in person with patients in the presence of their families and caregivers. Potential participants will receive a letter of informed consent.

c. Patients who complete a survey will have signed and understood an informed consent letter that encompasses both the survey and the interviews.

5. Procedure

a. The participants will experience a letter, a phone call and second phone call as needed, if they choose to participate an introduction to the researcher, information about the digital recording process, they will be interviewed and recorded, they will complete a survey and they will receive a final report of the findings. Data will be analyzed using three procedures: Descriptive coding will permit identification and categorization of common themes. Interpretive coding will be utilized if participant responses contain statements from which meaning may be derived. Explanatory codes will be developed if theoretical ideas or connections begin to emerge. The values obtained from each item in the Likert instrument will be summed to obtain a single score. Scores will be analyzed relative to their ordinal-level and/or interval-level.

b. Copies of the survey and interview questions are included, interview will be taped and reviewed.

POTENTIAL RISKS TO SUBJECTS

1 Interviewees might experience renewal or reconnection with the grief associated with the loss of the family who was in hospice care. Because this research is taking place within 12 months of the death of the patient, the effect of renewed grief will be minimized. Due to this timeline, patients will still currently be enrolled in the free MediCare bereavement counseling program. The researcher will consult with the bereavement coordinator to ensure that potential participants experiencing grief will not be at risk by an invitation to be interviewed, or an interview.

2 Potential benefits to the participants include: personal reward from knowledge of contributing to evidence based, enhanced services for others who share similar experiences.

3 There are no costs of any kind to the participants of this study.

4 There will be no reimbursements or payments to participants in this study.

5 All records will be kept confidential, and no identifying information will be disclosed. No names of any kind, pseudonyms or otherwise, will be used in the final report.

INFORMED CONSENT

"The experience of African American Hospice patient/family with Board Certified Music Therapy as a component of their Plan of Care."

My name is Elizabeth Gifford, and I am a graduate student at the University of San Francisco in the Doctorate of Nursing Practice, Health Systems Leadership program, conducting a project for my doctoral capstone project. You were selected as a possible participant in this study because you or your family member are currently receiving, or recently have received music therapy services as part of your hospice care.

The purpose of this research is to better understand the experiences of those involved in music therapy as part of hospice care. If you agree to participate, you will be asked to take part in a 30 minute interview which will also be audio-recorded. Your participation in this study will involve a thirty minute block of time which will be scheduled at your convenience.

There are some possible risks involved for participants in this study. It is possible you may have some questions or experience some feelings about being interviewed. You may or may not experience personal benefits from participating in this research project. Your participation contributes to the researcher's understanding of the experiences people have in hospice music therapy sessions. This could lead to more effective services being provided to others.

If you have any questions about the research at any time, please call me at 408-834-3484 or my instructor, Dr. Marjorie Barter at the School of Nursing University of San Francisco, 415-422-6792. If you have any questions about your rights as a participant in a research project, please call the IRB Administrator, University of San Francisco (415) 422-6091.

In order to ensure that appropriate music therapy treatment was provided, you or your relative's medical record will be accessed during the course of this study. Information about you that is reviewed in connection with this study will remain confidential. Names or any other identifying information will not be disclosed to anyone.

Participation in this project is entirely voluntary and if you become tired or uncomfortable, you may end the interview at any time and reschedule for a later date. Or you may choose not to participate in the study. Or you may choose not to participate in the study any further.

Your signature below indicates that, 1) you have read and understand the information provided above, 2) you willingly agree to participate in this study, 3) you understand that you may withdraw your consent and discontinue participation at any time without loss of services , and 4) that the related medical record may be reviewed. You will receive a copy of this form for reference.

Results of this study will be published and located in the University of San Francisco, San Francisco, California

Signature and relationship   Date

____________________________________   ________________________

Allscripts #: _______________

INTERVIEW QUESTIONS AND SURVEY

"The UMOJA Project: Use of board certified music therapy as a tool to minimize disparities, and encouraging utilization of hospice care by African Americans."

Interview Questions

To be asked during 30 minute interviews with informed, consenting patients.

1) How did the music therapy affect quality of life for the patient and family

2) How did the music therapy affect quality of death for the patient and the family and

3) Would you recommend hospice care with music therapy versus hospice care without music therapy, and why.

Survey
To be completed by informed, consenting participants after their 30 minute interview.

Demographics
Patient Age_____ Primary Diagnosis__________________
Co-Morbidities________________
Caregiver Category (circle all that apply): Family Friend Staff
Hospice Length of Stay_____________
Number of Music Therapy-Board Certified Interventions:________

On a scale of 1 – 5, please rate the following:

1	**2**	**3**	**4**	**5**
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

1) Board Certified Music Therapy enhanced the life experience	**1**	**2**	**3**	**4**	**5**
2) The personal, active presence of a Board Certified Music Therapist enhanced the experience of the music more than mechanically played music.	**1**	**2**	**3**	**4**	**5**
3) Board Certified Music Therapy should be available to all hospice patients and families	**1**	**2**	**3**	**4**	**5**
4) The Use of Board Certified Music Therapy would influence my recommendation to others to use Pathways hospice	**1**	**2**	**3**	**4**	**5**
5) The Board Certified Music Therapy assisted connection of family to patient	**1**	**2**	**3**	**4**	**5**
6) The Board Certified Music Therapy increased pleasant reminiscence	**1**	**2**	**3**	**4**	**5**
7) The Board Certified Music Therapy added a personal dimension not available through other disciplines	**1**	**2**	**3**	**4**	**5**
8) The Board Certified Music Therapists' services were NOT beneficial	**1**	**2**	**3**	**4**	**5**
9) The Board Certified Music Therapist benefitted family more than patient	**1**	**2**	**3**	**4**	**5**
10) The Board Certified Music Therapist benefitted patient more than family	**1**	**2**	**3**	**4**	**5**

INTERVIEW COVER LETTER

July 2009

Dear ___________________________________

Please be assured of my appreciation of your sadness and suffering, no matter the degree, associated with the terminality of your family member. My goal as a health care professional, fulfilling requirements for a Doctorate in Nursing Practice at the University of San Francisco, is to not only deliver quality hospice care and service, but to offer additional resources. You received board certified music therapy as part of your service.

I am asking that you participate in a thirty minute interview with me, to elicit from you some of the benefits of this complementary therapy. Your participation will quite possibly enable others to benefit from the inclusion of board certified music therapy in their hospice plan of care.

I will follow this letter with a telephone call seeking an appointment time with you and your family for this purpose.

Sincerely,

Lisa Gifford, RN, MSN, CHPN, CHPA.
Pathways Hospice Community Relations Liaison Nurse

From: Emma Baron, VP Quality Improvement
Pathways Hospice, East Bay Office
333 Hegenberger Road, ste 700
Oakland, Ca 94621

July 1, 2009
TO: Institutional Review Board for the Protection of Human Subjects
University of San Francisco
2130 Fulton Street
San Francisco, CA 94117

Dear Members of the Committee:

On behalf of the Not For Profit Pathways Hospice Organization, I am writing to formally indicate our awareness of the research proposed by Ms. Elizabeth Gifford, a Doctorate of Nursing Practice student at USF, (11311493). We are aware that Ms. Gifford intends to conduct her research by administering a qualitative question to persons who have received Board Certified Music Therapy, the Intervention related to the UMOJA Pilot Project.

I am responsible for Quality Performance and am a Vice President of the Organization. I give Ms. Gifford permission to conduct her research in our company.

If you have any questions or concerns, please feel free to contact my office at 1-800-900-0811.
Or 1-888-755-7855

Sincerely,

(Signed Hard Copy Available)

Emma Baron
VP Quality Improvement
Pathways Home Health , Hospice and Private Duty
585 North Mary Avenue
Sunnyvale, Ca94085

Appendix B: Three Transcribed Interviews

Interview 1: "Mable"

(50-year-old daughter of an 86-year-old male patient)

LISA: How did the music therapy affect the quality of life for the patient and the family?

MABLE: For my dad, who was the patient, he looked forward to the sessions. And there wasn't a whole lot in this last year of his life that he actually looked forward to. There were a few things like time with the family, especially if I brought him here for a family dinner, if he knew the grandchildren were visiting, and the music therapy. When we first started neither one of us knew what this was. Okay, this lady called and she says she's from Pathways and something about music. So let's just see what it is. And the first session I didn't attend, it was during my work hours. So Joanne went out and so when I got to see my dad that evening I said, "Did you have a visitor today?" "Oh yeah, it was so good! She was so good. She played her guitar and she had this little drum…" And he was just so excited. And every visit after that he had that kind of excitement because it allowed him to do things that he couldn't do. Or when the facility had their regular music person come in to meet with the whole group, that was boring to him.

LISA: I think the person has something to do—

MABLE: Has a lot to do with it because it's his. It's his.

LISA: You know, it's like, "My musician came to see me."

MABLE: So, he actually wanted the facility to hire Joanne for the entire group because he said her music was better and she understands and you can remember things with her music. And a lot of the songs that he selected were from times he was in the Army and she just had a wonderful catalog of songs. And he would think about something, "I want to hear something by Frank Sinatra." And she would have something from Frank Sinatra. So it just added a new dimension, a new joy, quite honestly, to his life. And that helped me. What I didn't understand in the beginning, I knew this was something for him, I didn't know this was going to help me. And it did. It helped me to kind of take part in his memories in the music and it kind of brought out the historian in him. He could talk about a song and what was going on in the world at the time of the song and it was just a really good time for us to remember.

LISA: Isn't that something? And might that not have happened?

MABLE: It would not have happened. There's no way it would have happened. We didn't have a vehicle to allow it to happen.

LISA: How did the music therapy affect the quality of the death?

MABLE: It actually helped to prepare, I don't know if it helped prepare him, but it did help prepare me. Although near the end of the sessions, which were near the end of May, his song selections were more and more about—I don't want to say death necessarily—but an end to something. And I paid attention to that. The songs were different. He wanted to hear "My Way". And I never knew the lyrics to that song before Joanne played it for us and I realize that's a guy who's ending his life and he's telling the world, "You may not have appreciated all the things that I did but I did this my way." And that was just so much who my dad was. That was totally who he was. And he wanted to hear songs that we used to sing at Mass. It was just different, it was a transition to the types of songs. And I remember telling my sister that something's going on because the songs dad's choosing are different, they're really different. But how it helped me was I was able to choose songs to dedicate to him and it helped me say things to him in a song that were harder to say just in conversation. Some of the songs that he selected opened up conversations and Joanne helped us with that because she could see that we were struggling to get to that point and she helped us get to that point.

LISA: That's what I think that it does too. Would you recommend hospice care with music therapy, would you recommend to your friends a hospice that had music therapy versus a hospice without music therapy?

MABLE: Absolutely, no doubt, no doubt. And at my dad's funeral service I asked Joanne to come and sing a song that she wrote with my dad. And it took some time before she performed to tell the audience how this came about and what this was. The other soloist, who was a friend of mine who sang songs at the service, was so touched that she went over to Joanne and said, "How do you do this? I want to learn how to do this. This is what I want my music to be for people. I want my music to be healing and I don't know how to do that."

LISA: That's great.

MABLE: And I just wanted to tell the congregation that this was something that helped us get to this point. I think it just helped me deal with it a lot better. And I really told my siblings, "You guys should have participated. Because I know you didn't want to because it was awkward and you weren't comfortable," I said, "But it just puts you in a different place."

LISA: Well, this is the stuff that I need to… I take this and write it up and take it down verbatim. Now that you've told me, I'm not allowed to ask leading questions like, "Did it help you connect?" But over the years, and I've been working with Joanne now since… at Heartland I worked with her, at Optimal I worked with her, and I just went out on a limb and I was the administrator, so kind of I was building consensus and so they were letting me do what I was doing, and I was building consensus, so taking care of the team. Everything was hunky dory and I have been impressed with—and it just leads you, I've talked with the director of the program up at the University of the Pacific—and that the guided imagery that can be done and the quality of their study and the quality that they have to… and the quantity of music that they need to know before they can become a board certified music therapist. And so you had Joanne. I had Ian Wilkerson, who plays, who now plays on a jazz station sometimes on Friday nights up in

Russian River or someplace. And Megan Hughes, she was the youngest, she was only 24, Ian was 29, Joanne was around my age and then Emily Sheehan worked with us too, so it was the four of them but Emily was pregnant so she just got to review the notes at the end, she didn't participate at all. But I did get the four of them so that they are tagged on with all this too, which to me is the least I can do for them because they did what they did for me and for the patients. But I think it's… somebody in Florida did a big study, taped music versus the personal intervention, and hands-down the personal intervention is the higher quality of intervention for people. So that's very cool. Well, I'm so glad I could do it for your dad. He was beautiful. And thank you for letting me… for saying, "Yes." You know?

MABLE: Yeah, no problem. I really appreciated Joanne. She was really wonderful.

LISA: She really is. She looks like such a wisp.

MABLE: I mean, she became our friend. She became our friend.

LISA: Good, good. I have seen her do things… I had a German patient once who was just… I really thought he was going to be dying in, like in seconds. She walked in, she did with her little bells, "Bing!" I don't know, she had the right note at the right time. Up he woke and started singing some German songs with his wife and everything. And he died that night. But everybody had a cool time.

MABLE: Really?

LISA: He was there, "Oompah, oompah, oopah," some old German songs. Fascinating, fascinating. But this is really a much… a very elevated, civilized understanding of what the human organism is. And not just something to work and work and work. So thank you very much.

MABLE: I also appreciated her encouraging me to sing because I don't like my voice. And I never thought I had a very good voice. My sister has a beautiful voice and my brother has a beautiful voice and so we were singing so many songs that I love. So I thought, "Okay, I'll sing and the hell with it." And now I sing all the time. I sing all the time. And I don't care what I sound like.

LISA: That's cool. That's so cool.

MABLE: I do it for me.

LISA: That really is amazing, isn't it? The little thing.

MABLE: When she told us about the last session I was like, "What do you mean? No, it can't be the last session."

LISA: Yeah because they just let me run it for four months. But I hope that all this would prove to them that they need to do it all the time.

MABLE: They have to.

LISA: And the places that I’ve done it have more business. I mean, whenever you try to make a change in health care you cannot make a purely aesthetic or ethical change or a moral change in the American healthcare system. You must tie it to the dollar or nobody will listen to you. But I think that Medicare is the one that foots the bill in most of the hospice in the United States and I think—Tom Harkin just introduced a bill in the Senate that alternative therapies should be reimbursed—but I think those hospices that provide certified complementary therapies should get a .5 or 1% or more on their reimbursement. And that would encourage people—

MABLE: That seems fair.

LISA: It does seem fair.

MABLE: When I was telling friends about this program they were like, “Really, really?” I was like, “Yeah, it is so cool.” And after Joanne performed at my dad’s service some of my friends came up to me and said, “That was so great.” Because she performed the songs that she wrote with my dad. And they thought that was just amazing.

LISA: It really is. It really is amazing. The younger music therapists, Ian had a gentleman who lived alone and he went in the hospital and Ian still went to the hospital and he made music for his family, his daughters… his daughters didn’t even know what kind of music he liked. They didn’t even know that Dad liked jazz. They didn’t even know some of the names of the people he liked because there is just such a distance between the music of the 20s, 30s, 40s and kids today.

MABLE: I will tell you, I knew my dad liked jazz, blues and some contemporary; I did not know he liked Broadway show tunes. And some of the songs he selected were Broadway show tunes. And then he kind of talked about, “Oh, I remember “Jesus Christ Superstar.”—I’m like, “What? Are you kidding me?”

LISA: Isn’t that something?

MABLE: “Wasn’t this song part of “Guys and Dolls”?” I said, “You are kidding me.” Yeah, he loved this program. He was amazing. He also liked it that no one else there was getting this. It was his, all his.

LISA: I think that means something. I think that means something.

MABLE: He liked to show off.

LISA: Another little lady that was getting it up in Oakland and she started singing with the music and her daughter said, “Mama, I didn’t know you could sing.” And she just said, this old lady said, “Honey, there’s a lot you don’t know about your mama.” And that daughter still remembers it. I just saw her on Sunday, I went by to see her on Sunday and she said, “That makes me laugh. Every time I think about Mama saying to me, “Honey, there’s so much you don’t know about your mama,” and the old lady just laid in bed like that. She never moved. She didn’t even turn to her daughter and say it. She just said, “There’s a lot you don’t know about your mama." The daughter will never be the same. She'll never be the same. So. Well, thank you very much for participating.

MABLE: You're very welcome.

LISA: And I really, really, really appreciate the opportunity and I can only say that your responses, of course, are music to my ears. And it makes the times when I was doing this and, "Oh, for God's sakes, what the hell are you doing this for? What difference does it make?" All my colleagues are looking at infection rates in hospitals and falls. And I'm going along, and even the Dean is going, "Here she is with her music." But the Chair of my committee said, "You know what? I think you're right. I think the thing that will make a difference is that, 'My kind of music is being played and somebody cares that much to do that.'" So the Chair for my committee has bought into it. All right? So—

MABLE: Don't give up.

(END)

Interview 2: "Sophie"

(50-year-old daughter of a 79-year-old female patient)

SOPHIE: I don't even know what kind of dog she is but when the lady came to see him Friday she said she's not a dog wingy dog but the wingy dog with the fur you call it something else.

LISA: A long-haired dachshund.

SOPHIE: That's it.

LISA: She's mixed you think, Sal? Where do you go to school, Sal? Not far? Do you walk?

SAL: I don't walk, I get a ride.

LISA: You do get a ride? What do you like about school?

SAL: I don't like school.

LISA: You don't like school *yet*.

SOPHIE: He don't like getting up.

LISA: Oh, you like to sleep late in the morning?

SOPHIE: I have to get him up like an hour ahead of time and he'll sleep 30 more minutes. I go through this every morning.

LISA: How old are you? Seven.

LISA: (*Inaudible talking*) Well, if there's anything else we can do for Mom you give me a call. You have my number on the cell phone… Pathways is helping taking care of Grandma. They try to make her as comfortable as possible where she's at because she can't come home yet. And they're trying to keep her comfortable.

SOPHIE: One day last week I just had a vision.

LISA: Did you?

SOPHIE: I had a vision of her dying. How I acted. Everything. I don't know why I had that vision but I had it.

LISA: Maybe something's coming.

SOPHIE: But she was in good spirits, that’s what I liked about her, she was in good spirits.

SAL: Mama, I had a nightmare about you.

SOPHIE: He had a dream that someone tried to make me jump off a cliff or something. I jumped off the cliff. And you were crying.

LISA: Were you crying?

SOPHIE: He woke up in the middle of the night, “They kept telling you to jump off the cliff.” He started crying. I had to pray for him and put him back to sleep and say, “You’re mama’s right here, I didn’t jump off the cliff. Still here.”

LISA: She got hurt.

SOPHIE: He told me one day (*inaudible*-2:57).

REBECCA: My dream was so not what Sal dreamed about.

LISA: What was your dream about?

REBECCA: My dream was that she had passed away and you know who was in the casket? Teesha baby.

SOPHIE: Oh Lord.

LISA: Which is Teesha? The one who is going to have a baby or the one that had the baby?

REBECCA: That had the baby.

LISA: Was the baby alive?

REBECCA: She was crying. Levar said he had a dream that I wouldn’t give him any of my strawberries.

LISA: Well, it’s nice to see young people that like school like you. It really is great.

SAL: (**Inaudible*-4:05).

LISA: So far. So far you don’t like it but you’ll like it in about a year.

SOPHIE: Yeah, you sure well.

LISA: Don’t you like to be smart?

SAL: I’m already smart.

REBECCA: What’s two plus two?

SAL: Four.

REBECCA: What’s 11 times seven?

SAL: 11 times seven?

REBECCA: What’s 12 times 12.

SOPHIE: That’s why you got to go to school. You got a little more to learn.

REBECCA: It’s 144.

LISA: Do you like to play sports? Do you like to play, do you like to dance or what?

SAL: I’m good at Karate. I can kick you in the face and your teeth fall out.

SOPHIE: Why would you want to do that? You want to do something like that? You don’t do Karate to hurt nobody.

LISA: You don’t want to hurt anyone, it’s about defending.

REBECCA: It’s about how to defend yourself when you’re in a fight.

LISA: Right. That’s right.

SAL: … kick your butt.

SOPHIE: Well, you got to watch your mouth you can’t just say anything in front of me. Oh Lord.

MAGGIE: Excuse me, I don’t mean to break your conversation.

LISA: You need mama?

SOPHIE: Yeah, we got to go pick up –

LISA: I can come back but thank you so much.

SOPHIE: You can come back anytime.

LISA: I want to see you again, all right? You’re a sweetheart. And, honest to God, she’s a survivor.

SOPHIE: Yeah.

LISA: Isn’t she? You got a great family. And you’re part of it and you’re the next generation.

(END)

Interview 3: "Clark"

(96-year-old husband of a 98-year-old female patient)

CLARK: Of course, that's not the excuse but my hands have a lot of age.

LISA: Would you say that the music improved things for you, it was a positive?

CLARK: Sure. The music was nice and she was playing it, she played the music. Sure it was.

LISA: I found that some people said that the music was something to look forward to. A lot of times when people are sick they can't walk, you know, they don't eat, there so many things that they lose but the music was something that they could look forward to.

CLARK: Yeah, that's true.

LISA: And Rachel used to tell me that you had songs that you wrote too a long time ago. You brought them out.

CLARK: A song that came to me—and I had two—but one went from me but the other one, it stayed with me and I kept it. I have four verses for each one of them so I'd have to go back and look around. The other one I'd have to go back and look the words up. Kind of re-remember them. But the other one, "Lord, don't let me walk this road alone..." most of that stayed with me. I had four verses and one, I could remember three and I had another one and made four versus out of it. So I put it in my suitcase and I'd have to go in and get it out. Did she give you any of the verses of it?

LISA: She did. She played it for me. You know how they say it gives you goose bumps? Like a tingle? Because it was so nice.

CLARK: My voice, my wind wouldn't hold out long enough to go through it. I'd have to stop and she'd have to stop playing, the tape, whatever she was doing. I got so I couldn't do all four verses at one time.

LISA: But it's a beautiful song, "Lord, don't let me walk this road alone." So if you… supposing one of your friends needed hospice would you be inclined to tell them to get one that has a music therapist?

CLARK: Sure I would.

LISA: Okay, I think it makes a difference in what we do. I think that one of the things that's important is that we treat people as whole people, as persons, particularly when they're real sick that we just, that they're not just a patient but they are a person and your wife was 98 –

SARAH: 94.

LISA: Are you 98?

CLARK: I'm 90.

LISA: You're just young, you're just young.

CLARK: But she was 94.

LISA: Okay, 94. But she had a long life as a person before she became a patient. You know? So at the end of life or as the end comes and people and people are going to pass on, it's nice to treat them as a person.

CLARK: That's true.

LISA: And I think the music helps with that.

CLARK: It did.

LISA: Now, we wouldn't have any music in the United States if it wasn't for the South, right?

CLARK: I think that's where it originated from.

LISA: I think so. I think those cotton fields gave us a whole lot of music.

CLARK: They sure did.

LISA: The resilience of all your kin and your folk that survived lots of stuff that wasn't good but you trusted in the Lord and the Lord showed you the way and you gave us music. You really did. We wouldn't have American music if it wasn't for the African-Americans in the South. Wouldn't have Dixieland, gospel, blues, and that's the real American music. We have a lot of other music that comes from different places but the real American music is from the South.

CLARK: Yeah, they had good voices. They really did. And it stayed with them.

LISA: Do you get to go to church?

CLARK: Yes, I went to church last Sunday. We had a church meeting last night so I intend to go to more of them.

LISA: Wednesday?

CLARK: A prayer meeting. Before my wife went down I was going to a prayer meeting every Wednesday. On Wednesday night we have Sunday school teachers meeting. They meet to teach. Each Sunday we have the same Sunday school lesson that we do Sunday we practice on it Wednesday night. One person gets up and teaches a lesson while the others listen and that's the way we do it. And then we have a Bible class that's about 15 minutes each Wednesday night. Not every one but mostly every Wednesday night when we have something else to do.

LISA: The folks keep pretty busy don't they?

CLARK: They sure do.

LISA: It's amazing, people keep busy. Visiting friends and looking after each other and making calls and it's wonderful in the community, in the African-American community, that you have this closeness. It's wonderful. You know, we don't have it that much in the white community, you know that?

CLARK: You don't?

LISA: We don't. We don't. We really don't. No, we kind of spread out and kind of get away from folks. But the African-American black community seems to hang together no matter what. You know? It's kind of beautiful. Eat sweet potato pie. Well, it'll be Halloween soon.

CLARK: Sure will.

LISA: We're already in October. Pumpkin pie. Do you think that having Rachel play the music with you and your wife was better than just turning the radio on?

CLARK: Sure it was. Because it was live.

LISA: Okay. And would you say that that kind of music should be available to everybody?

CLARK: I sure would.

LISA: Okay.

CLARK: It should be available.

LISA: Did you get a sense that your wife stayed a little bit more connected because of the music?

CLARK: Yes. Sure. Sure. She used to love to sing… she loved the music too.

LISA: Yeah. And none of the rest of the hospice team did what the music did. It was special, wasn't it?

CLARK: Yes, it was.

LISA: As good as the people were it wasn’t the same as the music.

CLARK: The music, it was something that we hadn’t been used to having. When we’d get sick it wasn’t something we were used to having. We would play records and things, but live music like that, we didn’t have. That’s the first we had.

LISA: Well, I’m glad I was able to do the first for you. Would you say that the music benefited your wife and you equally or one more than the other?

CLARK: Well, I would say it was probably almost benefited her as much because, you see, she was ill and she would be able to respond better if she hadn’t been. But sure, I would say it benefited her just almost as much, just about as much as it did me. That’s what I would say.

LISA: Did you have a nice funeral for her?

CLARK: Yes, we did. And then they took her to the cemetery and they let us see her let her down. Something, I thought I couldn’t stand it but if I hadn’t had somebody there with me I wouldn’t have wanted to stay my myself to see that by myself. But I had my relatives, my daughter and my nephew, they was there. And somebody else was with us. I think. And when hospice, Albert, was there.

LISA: He was a nice guy wasn’t he? Albert Neville. Yeah, he was a nice guy.

CLARK: And there was one of the hospice women there too.

LISA: That was nice, that was nice. It could’ve been Joy or Patty?

CLARK: I think it was.

LISA: Mercy?

CLARK: I know it was one there.

LISA: Nancy?

CLARK: I just remember the name…

LISA: Did she have long hair or short hair?

COTTON: I don’t remember now. But I know she was there. Now, Albert, he could tell you which one it was.

LISA: Okay, he’ll tell me. He’s a real nice fellow, isn’t he? My God, what a nice guy. What a good, good person. You know, there’s a lot of people that don’t use hospice because they think they shouldn’t have help so if anybody in your family or any friends or anything, you tell them to call and we'll see that they get the help. Because it's so much better when the person can be at home, when they can be at home because the hospital and the nursing home is so lonely and it's so nice to be at home. But there's a lot of people that don't know about it so don't hesitate to tell people that you had it and that it was good and they ought to find out about it. I'm going to give you this piece of paper that tells you my name and what I'm doing and what I'm trying to prove so that I can get music for everybody. And the telephone number is down there and everything.

CLARK: "…the experience I've had at American Hospice patient family with…

LISA: "…board-certified music therapy as a component…"

CLARK: "…as a component of the plan of care. My name is Elizabeth Gifford and I am a graduate student at the University of San Francisco with a Doctorate of Nursing Practice." Mmhm! "Health Systems Leadership Program. I am conducting a project for my doctoral…"

LISA: It's like my dissertation. "You were selected as a possible participant because you or your family member recently received music therapy. The purpose of this is to better understand the experiences of those involved in the music." And so we're doing this 30 minute interview here. You know, when we do this, I am sensitive that talking to you about your wife might bring up memories, and I don't mean to make you sad but I hope you're going to remember good things, and this all could lead to more, better services for all people. Then my telephone number is there and the professor who is the chair of my committee –

CLARK: Oh yes, I see. "If you have any questions about the research at any time please call me at 408-834-3484."

LISA: That's my cell phone.

CLARK: "…or my instructor, Marjorie Barter…"

LISA: And she's my instructor.

CLARK: "…at the School of Nursing, University of San Francisco."

LISA: And that's her number. And the reason I printed this up is so that I could leave something with you so that you know what I'm doing. I said to your friend over here, I said, "Don't you just let the white woman go up there and see that man without coming up to see what's going on." This is your dad? No kidding. Wow.

CLARK: Yeah, this is my daughter.

LISA: What's your first name?

SARAH: Sarah.

LISA: Sarah. Isn't that great. Were you ever here when the music was played?

SARAH: No, I missed the music. I was here during a lot of the (*inaudible-18:58).

LISA: Do you live near here or did you come from –?

SARAH: Mississippi.

LISA: Mississippi. And so you just came back here for another visit? Did you go home since?

CLARK: She was here for the funeral.

LISA: Oh, you were here for the funeral. Okay. You're not going to move to Oakland, huh? You're going to stay in Mississippi?

SARAH: Yes.

LISA: Are you going to have him down to visit? Will he come?

SARAH: I would (inaudible-19:30) him back home but he's not ready for that yet.

LISA: He wants to be in his place. That's really nice that you honor that. Yeah. Because he's got friends that can look in on him, right?

SARAH: Yes, I really wanted him to go but, like I told him, what's important is his happiness. He'd be happier here.

LISA: Yeah, I can see that he knows where everything is, he has routines here… Do you get to see your doctor? Do you see a doctor?

CLARK: Yes, I have a doctor at Kaiser. I'm supposed to go up there tomorrow evening for some back therapy.

LISA: Okay.

CLARK: I hurt my back and I've been walking with a stick ever since.

LISA: No kidding.

CLARK: (*Inaudible-20:39) to put the stick that day, cane down but I hope they can help me to walk better. That's the main thing.

LISA: Sarah, are you going to go with him to Kaiser tomorrow?

SARAH: I don't know. Usually… if he was real sick or something, yes, I would go, but he can drive himself there.

LISA: Amazing. You're a wonderful, wonderful man.

CLARK: Yes, I live to get my age.

LISA: That’s beating most people. The average age is only 78 that people live. You got a long time.

CLARK: Yeah, a lot of people don’t drive till they hit 90.

LISA: I know, I know.

CLARK: I had a brother, he lived to be 94. I think he was driving up until he was about 93.

SARAH: He was driving a school bus there for a while.

CLARK: Yeah, he drove a school bus for a long time. I think when he was in his 80s.

LISA: Wow! Good stock, huh?

CLARK: Sure was. He stayed in there a long time.

LISA: So I’m going to leave that with you and then when I visit all the people that had the music I’m going to come back and tell you what the results are. Okay?

CLARK: All right.

LISA: Because I think you deserve to know that.

CLARK: Thank you.

LISA: So this is the same one here and if you just sign this here that you read this, this is the same one. I have to make sure that you know that I didn’t confuse you. You got to be careful, I’m so glad you’re here. I’m so sensitive about going to see elderly people and they’re all alone… Are you the only child?

SARAH: There is another one but she’s not here.

LISA: Okay. Most of the time it’s just you, Sarah. Who gave you the name of Sarah? Your mother? It was named after who?

SARAH: It was a teacher she told me that she had, not that she had, that she knew of.

CLARK: A young woman that was named Sarah. I remember her.

LISA: You do?

CLARK: Yes.

SARAH: I used to ask her, “Where in the world did you get Sarah from?”

LISA: It’s a very pretty name.

SARAH: She thought it was at the time.

LISA: Did you get a middle name too?

CLARK: Sarah Grant.

LISA: Oh, that is special. That is special. I bet you never met anybody else who was Sarah Grant Woolsey, did you?

SARAH: No. I went to school with Sarah, my sixth grade teacher, my seventh grade teacher, was Sarah. And then I got her again in high school. You know, she’s still living, she’s right down the street from me.

LISA: Really? In Mississippi? Really?

SARAH: Mm-hm.

LISA: It’s a good life, isn’t it?

SARAH: Yes, it is.

LISA: Hard sometimes but...

SARAH: Hard but fair. It’s good.

LISA: Well, I’m glad to meet you finally. Rachel told me all about you. It’s real nice. You call me if anything else comes out.

CLARK: That’s your card you gave me?

LISA: That’s my card and that’s the same number that’s in the letter there. Okay? That’s my card. And that’s the same number that’s in here too. That’s me. Okay? But I really appreciate you giving me some time to do this. I’ve been using music with patients since 1989.

CLARK: Oh.

LISA: I used to do it when people had surgery, like outpatient surgery, they had to get their cardiogram and blood work done and I would meet with them before and see if they were safe for surgery. And then I would ask them what kind of music they liked so that when they came they had something to listen to and I’d give them a headset so they could relax and kind of just go into themselves waiting for the surgery instead of just kind of waiting. And they laughed at me when I first did it. They really did. They said, “Oh my goodness, what’s she doing now?” But soon if the patient went to the operating room without the headset the doctor would call me and say, “What’s the matter? Don’t we do this music anymore?” Because it helped the people relax.

CLARK: Yes, it does.

LISA: And if you're relaxed you do surgery better. So that was my thing. So I've been working on this for a while. I've known Rachel for, I've worked with her before. So I think that we've kind of lost some of the personal in the health care. And I'm hoping that by being attentive to music that it's personal. We could bring a little bit of personal back in because then I think people can handle the illness better and the sadness and the whatever. If they can connect with who they were before, that sort of thing. That's my idea, anyway. I'm sticking to it.

CLARK: Yes, it will. They could remember when you were coming there, if they're deceased they wouldn't, but the survivors would remember when you were there singing and playing music.

LISA: I have one daughter of a man who passed on and she never used to sing. She had a sister who was a good singer but when Rachel was there Rachel would make, you know, encourage her to sing. And now that her father's passed on she finds herself singing. Isn't that nice? It makes it all more gentle.

CLARK: Yeah, music is soothing.

LISA: Yes.

CLARK: Sure is.

LISA: Well, thank you, my friend, for letting me come. You even put the heat on for me, you were very nice to do that. I'm sure everybody doesn't get the heat. That was very, very, very nice.

CLARK: I hope it wasn't too warm.

LISA: No, it's fine, I love to be warm. I hate to be cold. I hate to be cold. I have a car that –

(END)