Support for the Supporter: Dance/Movement Therapy with Community Dwelling Spouses of Long Term Care Residents Diagnosed with a Dementia Related Illness: A Clinical Case Study

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SUPPORT FOR THE SUPPORTER:  
DANCE/MOVEMENT THERAPY WITH COMMUNITY DWELLING SPOUSES  
OF LONG TERM CARE RESIDENTS DIAGNOSED  
WITH A DEMENTIA RELATED ILLNESS  

A CLINICAL CASE STUDY  

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Thesis submitted to the faculty of Columbia College Chicago  
in partial fulfillment of the requirements for  
Master of Arts  
in  
Dance/Movement Therapy & Counseling  

Dance/Movement Therapy and Counseling Department  

December 2010  

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Abstract

This thesis is the summation and findings of a clinical case study regarding dance/movement therapy with community dwelling spouses of long term care residents who have been diagnosed with a dementia related illness. The intention of this research was to raise awareness of the underserved population of supporters, and to examine how dance/movement therapy could serve to aid in the treatment of the issues community dwelling spouses face. Due to the scarcity of the literature on the primary topic, various relevant topics were examined. Research was found proving that anxiety, depression, and stress are the most prevalent issues being faced throughout the populations of in-home and community dwelling caregivers. Yet, issues regarding identity, roles and responsibilities, guilt, and boundary ambiguity were also of importance within the literature. In order to determine the presenting issues of the clients in this particular clinical case study, a needs/assessment treatment plan was implemented, and the Relative Stress Scale was administered for pre and post test results of the six week dance/movement therapy sessions. During these sessions, the clients were afforded the opportunity to express themselves in regards to their current situations as community dwelling spouses. Universality and normalization of feelings were emphasized throughout the sessions as the clients became more open with each other and themselves. Evidence of an increase in self esteem, a positive change in attitude, the development of positive coping skills, and a physical, mental, and emotional decrease in symptoms of depression and anxiety resulted from the sessions. The results of this study correlate with the findings of previous research and suggest a reason to address the needs of this population. Questions and implications for further research are discussed as a means of suggestion for how these needs might be met.
Acknowledgements

I would like to extend many thanks to all those who were part of my process. But first, to the participants who agreed to partake in this journey with me. Your willingness to try something new so that others like you may one day be helped was inspiring. You have made a difference already. Also, to my Grandmother for without her, I might not have taken this path. Thank you to my close friends and family who, throughout the trials and tribulations that I thought might take me over, were there offering consistent support. A special thanks to my advisors and supervisors who were standing in my corner the entire time: Laura Allen, Lenore Hervey, Jessica Young, Deb Del Signore, and last but certainly not least, Rebecca Froman.

Finally, it is with much gratitude and everlasting awe that I am forever indebted to one special person. You awakened the last bit of fight within me when I thought I had lost, and helped me to once again find the undying ability to persevere. You told me to not give up during the 12th round and held my hand until I could employ my resilience yet again. Thank you for increasing my already high tolerance for facing adversity and looking a challenge straight in the eye; because of you I am that much stronger. You know who you are.
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Chapter I: Introduction

Dementia related disorders affect not only the individual dealing with the physical manifestation of the disease, but those in close contact as well. For many, the other person significantly impacted is the spouse. As stated in Robinson, Clare, and Evans (2005), “dementia is not experienced by individuals in isolation. Many people developing dementia live as part of a couple…” (p. 337). There is much research done on dementia related disorders, yet only a small portion is devoted to the impact on couple relations (Daniels, Lamson, & Hodgson, 2007). Furthermore, there is even less research that has been conducted concerning the effects on the community dwelling spouse after institutionalization has occurred (Kaplan, 2001).

Chances are, the community dwelling spouse was first serving in the role of caregiver. Therefore, not only was he/she dealing with the slow progression of the disease taking over his/her spouse, this spouse was also taking on more responsibilities and roles. At some point, with careful consideration and many issues to weigh, the step was taken to move the spouse with a dementia related illness into a long term care facility. This step, in and of itself, has many implications, and can leave both spouses feeling the effects of the separation. However, the difference between the two spouses can, oftentimes, be easily observed. The spouse that resides in the long term care (LTC) facility is receiving round the clock care from a team of professionals whose sole job is to maintain his/her well-being. While, on the other hand, the community dwelling spouse is dealing with issues concerning finances, guilt, separation, identity, etc. and can still often be seen spending time on a daily basis at the facility where the other spouse resides. The community dwelling spouse is physically, mentally, and emotionally present for his/her loved one, giving support in every way. But, who supports the supporter? These supporters make up a subpopulation that, in comparison, goes somewhat underserved.
They are the community dwelling (CD) spouses: someone who lives in the general community and does not get extra support as part of his or her day, unless they seek it (see Appendix A).

After the transition to long term care, the CD spouse no longer has the burden of physically caring for his or her spouse; however, there are many other stressors that these spouses still endure that should be addressed. One common stressor that CD spouses face is the financial repercussions of the decision to move to long term care. Many try and utilize savings and governmental provisions, such as Medicare or social security. However, for others, this isn’t enough; some CD spouses re-enter or continue in the workforce to supplement income in order to pay for the cost of long term care living. This can add another layer of stress in dealing with schedules in order to spend time at the facility, or taking days off if something happens to the spouse in LTC. Worrying about the spouse residing in the facility is another aspect of stress. This can include the feelings that someone else might not be able to care for the loved one as well as the spouse thinks he/she can.

Another aspect is an effect of the culture of the older generation. This generation oftentimes abides by the cultural norm that regards the woman as the familial caretaker. The caretaker role can become her identity. When this role is removed from her, identity issues can arise. Alternately, the male in the household may feel that, at this point in time, it is his duty to reciprocate as the familial caretaker. If his spouse is placed in LTC, he may feel a sense of guilt and/or helplessness (Daire, Torres, & Edwards, 2009; Gladstone, 1995).

The purpose of this research is to examine the ways in which dance/movement therapy (DMT) can be a supportive counseling tool to aid in the treatment of issues experienced by CD spouses of LTC residents diagnosed with a dementia-related illness. In addition to furthering the field of DMT (see Appendix A), a long term effect of this study may be the possible impact that
this research could have on the support services found within LTC facilities from the point of admission throughout the full institutionalization. The project may increase awareness in regards to the treatment approach of the issues that arise specifically within this sub population. By executing this study, there is hope to answer the question: How can DMT be a supportive counseling tool in the treatment of an individual whose spouse, due to a dementia-related illness, resides in a long term care facility?

As a clinician, I plan to answer these and other clinical questions with the results of this study. Acting through a multi-modal framework, I utilized the concepts of different theorists in the areas of dance/movement therapy, movement analysis, and counseling. From the arena of dance/movement therapy, Marian Chace’s group work techniques and foundations served as a mode of structuring the sessions through a check-in/assessment, warm-up, theme development section, and closure of the group. Her ideas of thematic work and therapeutic relationship were employed through using her core concepts including body action, rhythmic group activity, and symbolism. Dance/movement therapy pioneer, Alma Hawkins’ perspectives and theories on relaxation and imagery also proved useful for interventions within the sessions. She believed that seeing, feeling, imagining, and transforming within the creative process could lead to healing (Levy, 2005). For assessment purposes, I used the BESS (Body, Effort, Shape, and Space) aspects of Laban Movement Analysis (LMA). This form of movement analysis is often used in the field of dance/movement therapy to inform the clinician as to the ways in which to approach interventions from a body centered perspective. A more succinct definition of LMA and other useful terms can be found in the glossary in Appendix A. As for the counseling framework I was working from, humanistic psychology played a major role in the way that I interacted with the clients. I acted as a guide in their processes, and tailored the sessions toward
their needs based on the initial assessment and any organically evolving material. I felt that it was very important that I did not approach the sessions with an agenda; yet, I provided the container for the processes to unfold, an ideal that the principles mentioned above and the literature to be examined fully support.

In the following chapter, supportive literature for the questions which fueled the clinical case study will be explored. The examined areas include literature in regards to dance/movement therapy, counseling, and the mental, emotional, and physical effects of being a community dwelling spouse.
Chapter II: Literature Review

In 2010, “250,000 people will be diagnosed with Alzheimer’s disease…and by 2040, an estimated 11 million Americans will have [it]” (Shallcross, 2010, p. 38). With the increase in the occurrence of Alzheimer’s disease and other dementia related illnesses, there will concurrently be an increase in the number of spousal caregivers. Due to various reasons, including but not limited to health concerns, safety issues, familial strains, or increased positive attention by the public placed on LTC facilities, placement of the spouse with the dementia related illness may become a result of the disease. However, once the spouse has been placed in LTC, the burden that the caregiver spouse once carried, does not completely disappear. Although there is evidence that caregiver burden is reduced once long term care residency is established, research concludes that stress on the CD spouse continues, simply in different forms, and that the care giving does not end with institutionalization (Carpenter & Mak, 2007; Gaugler, Roth, Haley, & Mittleman, 2008; Gladstone, 1995; Kaplan, 2001; Kaplan & Boss, 1999). Therefore, if the caregiving does not end, neither do the consequences of it. Caregiving becomes, for many, a career (Gladstone, 1995; Kaplan, 2001; Sidell, 1999).

Dementia Defined

For many, the reasons for institutionalization come from the resulting complications of a dementia related illness. While Alzheimer’s disease is one of the most well known and common forms of dementia, there are a few others as well. According to the *DSM-IV Made Easy: A Clinician’s Guide to Diagnosis*, a diagnosis of dementia is constituted by a decline in functioning, memory loss, other cognitive deficits (including agnosia, aphasia, apraxia, or loss of executive functioning), and cognitive impairment (Morrison, 2006). Conclusions from one study found the prevalence of dementia increases with age by approximately doubling every five years (Gallo & Lebowitz, 1999); and with 10 percent of people over the age of 65 with a diagnosis, it
is likely that many families are affected in some way (Gallo & Lebowitz, 1999). In the most recent information published from the Alzheimer’s Association, “although families generally prefer to keep the person with Alzheimer’s at home as long as possible, most people with the disease eventually move into a nursing home” (Alzheimer’s Association [AA], 2010, p. 7). This illuminates the fact that eventually there is a separation of the spouses when one moves into a facility, creating a LTC resident and a CD spouse. Alzheimer’s disease and other dementias are “fluid, constantly changing and unpredictable, which means that for the…caregiver, there are no consistent, easy fixes” (Shallcross, 2010, p. 38). It is this unpredictability and dis-ease, coupled with the spouse with the illness residing in a LTC facility, which creates stress and burden on the spouse left to stay within the community.

**The Community Dwelling Spouse**

When one half of a marital dyad is placed in LTC with complications from a dementia related illness, the spouse left living within the community can be easily forgotten, figuratively and sometimes literally. Not only does the CD spouse suffer the emotional loss of his or her other half via the effects of dementia, but in the physical sense as well. This change in living situation can place a great deal of stress and burden upon the CD spouse (Gladstone, 1995). The role that this spouse has previously embodied undergoes a change with LTC placement of the spouse stricken with a dementia related illness. There are many studies that have focused on the caregiver before the move to LTC placement. There have also been studies focused on keeping the marital relationship alive while in LTC. Likewise, there have been numerous studies conducted concerning the spouse residing in LTC with a dementia related illness. However, the studies simply concerning the CD spouse are few and far in between. One study found that:

The perspective that tends to dominate much of the literature is that care by family
members is provided solely to older adults living at home. When caregivers are followed over longer periods of time, it becomes evident that family caregiving responsibilities do not end with institutionalization of the disabled relative. (Gaugler et al., 2008, p. 421)

In essence, just as the spouse is the caregiver with an often thankless job before LTC placement (Gaugler et al., 2008; Gladstone, 1995), his or her contribution and well being is often overlooked within the context of the literature once the move has been made. These spouses are now completely in charge of all the aspects of home life, finances, and day to day occurrences; as well as, visiting the institutionalized spouse, overseeing and managing his or her care, and sometimes continuing care while visiting the facility. Somewhere within all of these responsibilities, these CD spouses are expected to be taking care of themselves alone. Many times the CD spouse’s health begins to suffer under the weight and stress of taking care of everything. These spouses can be seen as still living as a caregiver, just in a different form (Gladstone, 1995).

**Experience of the CD spouse.** According to Beckham and Giordano (1986) and Daniels, Lamson, and Hodgson (2007), the healthy spouse feels a great sense of loneliness in the relationship. This can also lead to feelings of being unappreciated and exploited. Also, as examined in Robinson, Clare, and Evans (2005), “Partners appeared to find it difficult to manage the loss of their independence alongside an increased dependence of the person with dementia, and this left them feeling stressed, frustrated, and depressed” (p. 342). In accordance with this loss of independence, it is also found that partners suffer a loss of the relationship as it once was (Beckham & Giordano, 1986). The feelings aforementioned can lead to other feelings of anger and resentment. Anger, according to Beckham and Giordano (1986) “may be a direct reaction to the ill spouse’s paranoia, forgetfulness, inconsistency, or obstinacy…anger is often suppressed
and then contributes to guilt…because of incompletely acknowledged hostility and an inability to relieve the suffering mate” (p. 259). Likewise, in Robinson, Clare, and Evans’ (2005) study it is found that “as memory difficulties worsened, some partners appeared to find it more difficult to stay calm and not get angry with their spouse for repeating themselves or being unable to retain new information” (p. 342). Yet another feeling as part of the healthy spouse’s experience, is the idea that they “may feel burdened by work; guilty about taking away another’s rights, privileges, and roles; and grief at the loss of a more equal and reciprocal partnership” (Beckham & Giordano, 1986, p. 55). Lastly, parallel to the loss that the spouse diagnosed with dementia deals with, the partner spouse experiences a range of losses as well. These can include feelings of loss of a support system, a previous lifestyle, and one’s confidante (Dempsey & Baago, 1998).

The concept of the needs of the healthy spouse is described in the literature in terms of coping strategies. Obviously, since there is no cure for the disease, the only option is to find strength in coping skills and implement them consistently. For example, “partners found that…trying to maintain a positive state of mind and using relaxation strategies facilitated their ability to cope” (Robinson, Clare, & Evans, 2005, p. 343).

**Mental health implications of being a CD spouse.** There are many mental health implications for the CD spouse following and throughout LTC placement of his or her spouse with dementia. While anxiety, depression, and stress are the most prevalent throughout the literature, identity issues regarding role and responsibilities, guilt, and boundary ambiguity are also noted.

**Increased risk for anxiety and/or depression.** Perhaps the most prevalent issue that arises as a mental health implication for the CD spouse is anxiety and/or depression. As seen in previous literature, CD spouses are under much stress and according to the Harvard Health Letter
“(2007), “depression and anxiety, which afflict millions of Americans, can be caused or exacerbated by stress” (p.3). Other recent research also suggests that, “caregivers have a higher prevalence of depression and anxiety” (Carpenter & Mak, 2007, p. 48) and experience guilt and depression (Gladstone, 1995; Tornatore & Grant, 2002) even when the stereotypical caregiving ends and the partner is transferred to a LTC facility. Also, in Gaugler et al., “more recent studies conclude that [nursing home admission] results in guilt, anger, anxiety and depression in caregivers of people with dementia” (2008, p. 422). Most of the studies conducted were either quasi-experimental or qualitative. Very few studies focused on single cases, or had quantifiable data. However, in Gladstone’s (1995) qualitative study, community dwelling spouses and family members’ opinions, feelings, and reactions to LTC were documented:

A husband appeared to visit his wife with such constancy that his own well-being began to suffer. He remarked “my time is taken up and it’s my fault. My family says ‘dad, you don’t have to visit mom everyday. Other people in the family go. You should relax and go away for a holiday.’ But I can’t. She controls everything I do. My doctor says I’m foolish. He says I must learn to relax. I can’t learn how to relax.” (p. 504)

This example illustrates how the situation of LTC can provoke anxiety, which can in turn promote depression and feelings of guilt. Furthermore, according to the Alzheimer’s Association 2010 Report, “about 1/3 of family caregivers of people with Alzheimer’s disease and other dementias have symptoms of depression” (p. 28). Cooper, Balamurali, Selwood, and Livingston’s (2007) findings explore this aspect and the lack of care associated with it, revealing, “although anxiety disorders and symptoms may be the commonest mental health problem in caregivers of people with dementia…and are frequently comorbid with depression…, their treatment has been relatively neglected” (p.181).
Feelings of guilt. CD spouses are usually the ones to make the decision as to whether or not to place the spouse with a dementia related illness in LTC. Therefore, although the CD spouse appears to know that the care received will be greater than what he/she could provide alone, the guilt aspect of placing the loved one in another location can be a consequence of this decision (Tornatore & Grant, 2002). These feelings of guilt come from the perceptions of the CD spouse as well as society. Literature suggests, “the societal misconception still exists that when families place their loved ones in a nursing home, they ‘dump’ them there and cease to be involved in their lives” (Tornatore & Grant, 2002, p. 503). Also, Harper and Lund (1990) conducted a study that documented stress in spousal caregivers of institutionalized mates with a dementia related illness. In accordance with the research, guilt is a component of the mental health implications of LTC on the CD spouse in more ways than one. Not only is there guilt about the institutionalized spouse residing away from home due to the CD spouse’s decision, but also surrounding the amount of time spent visiting those in the facility. This can impact the well being of the CD spouse as aforementioned due to the inability to take time and care of oneself as a result of guilty feelings. Lastly, the feelings of guilt can be exacerbated by engaging in self care activities, as evidenced by the case example in the qualitative case study conducted by Daire, Torres, and Edwards (2009) in which the cultural background of the wife prevented her from taking care of herself before completely tending to her husband.

Role, identity, and boundary ambiguity. When the spouse with a dementia related illness is placed into a LTC facility, the dynamic of the spousal relationship invariably changes. Most CD spouses have some form of in-home caregiving experience before a decision is made. Therefore, when the option to move the spouse to LTC comes into play, the role that was previously served by the CD spouse changes as the duties performed become absorbed by the
workers at the LTC facility. The CD spouses can feel the push-pull of the ambiguous role and boundary shift as they try to adjust to the new dynamic (Kaplan, 2001; Kaplan & Boss, 1999). While the spousal caregiver role in and of itself “comes with the…challenge of managing one’s own personal care needs and affairs while managing the personal needs and affairs of a loved one” (Daire, Torres, & Edwards, 2009, p. 67), there are many other components that are added or taken away as the LTC stay lengthens (Kaplan, 2001). “It is possible that the role that [he/she] played in the past is no longer relevant” (Ade-Ridder & Kaplan, 1993, p. 14). This constant change in the role and responsibilities of the CD spouse can add to stress and increase the feelings of boundary ambiguity as the spouses learn and re-learn their identities (Kaplan, 2001; Kaplan & Boss, 1999). Furthermore, the CD spouse:

must adjust to a variety of experiences: not being needed as much, living alone, not having the daily stimulation of support services entering the home, accepting the present situation, and forming relationships with the partners’ new caregivers. (Brubaker as cited in Ade-Ridder & Kaplan, 1993, p. 18)

As evidenced by the literature, there are many changes in the role and identity of the CD spouse as the stay within the LTC facility lengthens and the disease progresses. In addition to the other roles that the CD spouse takes on, Brubaker is quoted in Ade-Ridder and Kaplan (1993) stating that CD spouses also add the role of case manager to his/her role set:

The community dwelling mate visits and provides services in concert with the facility and the staff. Support offered to a partner may include visiting, advocating for the spouse, purchasing items unavailable at the facility, feeding, taking the spouse out of the facility, and providing other forms of physical, social, and emotional care. The healthy spouse can be said to become a case manager for his or her partner. (p. 19)
As evidenced by the information above, and in accordance with the literature findings, caregiving does not cease when an individual is moved into a LTC facility, yet it is changed to fit the needs of the situation at hand. Likewise, the role of the CD spouse changes to fit the needs of the responsibilities that he/she undertakes. The levels of stress that the CD spouses experience remain high throughout the duration of the LTC stay (Alzheimer’s Association, 2010).

**Social and lifestyle implications.** Along with the many mental health implications of a spouse residing in LTC, a CD spouse experiences social and lifestyle changes as well. According to the literature, the way that the CD spouse relates to and associates with members of the community, as well as his/her previous social circle, is hindered by the change. Also, aspects of the CD spouse’s lifestyle change drastically, including but not limited to the financial changes due to the expenses having to do with LTC placement of the spouse with a dementia related illness.

**Lack of social support.** When a spouse is diagnosed with Alzheimer’s disease or another dementia related illness and remains at home, the illness can easily become part of the conversation between the caregiving spouse and his/her social interactions within the community. Other people are curious and want to know how the afflicted spouse is doing. However, once LTC placement is sought and established, the CD spouse may experience a type of isolation (Kaplan, 2001). In a recent study involving CD spouses, one stated, “‘They [friends] always used to visit before when (name) was here [at home]. And now that he isn’t here, I feel like I’ve been left like a hot potato, you know. Or, I’m a strange creature. That’s the hard part, I think, living in a community’” (Kaplan, 2001, p. 93). This feeling of isolation breeds upon itself, with the CD spouse in turn not wanting to participate in social activities for fear of feeling unwelcome, like an outsider (Kaplan, 2001). They feel “a loss of contact and interaction with
others, [and a] generally low involvement in community life” (Martin, Miranda, & Bean, 2008, p. 50). This separation from the community and previous social ties contributes to possible feelings of loneliness as well as breeds thoughts of hopelessness (Daire, Torres, & Edwards, 2009; Gladstone, 1995; Stephens & Qualls, 2007). Also, as the CD spouse becomes more isolated from the outside community, the prevalence of a lack of social support rises. In Harper and Lund (1990), lack of social support “accounted for 25 percent of the total variance in burden” (p. 254) as felt by the CD spouse. This can be further explored in conjunction with the role change of the CD spouse in Martin, Miranda, & Bean (2008), “When people are unable to adopt new social roles and activities, they increase their susceptibility to anxiety, depression, and social isolation since they lack the social supports that help us defend against life stressors” (p. 52). Some spouses begin to adapt and use the LTC facility as a “social outlet” (p. 51); however, many do not.

**Financial constraints.** Admitting and keeping a spouse in LTC is a major financial undertaking, whether governmental monetary support is included or not. For many CD spouses, the economic downturn has made it even more difficult to continue to pay for LTC.

For many CD spouses, governmental support is a major reason that his/her spouse was able to reside in LTC; without which, the expenses would be too costly. However, according to the Alzheimer’s Association’s 2010 Report, “Medicaid is the only federal program that will cover the long nursing home stays that most people with dementia require in the late stages of their illness, but Medicaid requires beneficiaries to be poor to receive coverage” (p. 39). Therefore, even if the family is simply getting by and living just above the poverty level, they may need to supplement the household income. Unfortunately, “even for older people whose incomes fall comfortably above the median, the costs of home care, adult day center services,
assisted living care or nursing home care can quickly exceed their income” (Alzheimer’s Association, 2010, p. 44). This usually means returning to the work force for the CD spouse; although, for many, the need for free time to visit the spouse in LTC does not allow for a structure work schedule. If the CD spouse is able to manage holding a job, the responsibilities of the daytime job and the flexibility that is needed when a spouse resides in a LTC facility can lead to missed shifts, frequent tardiness, unreliability, and extra stress on the CD spouses themselves, possibly resulting in consistently changing jobs or losing them all together (Carpenter & Mak, 2007; Martin, Miranda, & Bean, 2008).

**Physiological implications.** A major implication of having a spouse residing in LTC is that of the impact of stress on physiological health. Stress can manifest in many ways including but not limited to asthma, arthritis, gastrointestinal issues, sleep disturbances, mood changes, headaches, muscle soreness, etc. (Carpenter & Mak, 2007; Daire, Torres, & Edwards, 2009; Harvard Health Letter, 2007). This can be especially dangerous to the aging population whose health is decreasing with time, making them more susceptible to illness (Carpenter & Mak, 2007; Fersh, 1981). These issues with health and stress can be attributed to the fact that for a CD spouse, “with so much to do for a partner, one’s own diet, sleep, exercise and other self-care may become secondary” (Carpenter & Mak, 2007, p. 48). These spouses “often neglect individual physical needs, risking their own health by over-functioning in the caregiving role” (Kaplan & Boss, 1999, p. 3). One spouse expressed this idea in the Robinson, Clare, and Evans (2005) study, stating “‘You’ve got to think ahead all the time…I try and think of everything’” (p. 342). More recently, Daire, Torres, and Edwards (2009) took this idea further in their case study and coined these caregivers “supercaregivers” (p. 69) for this reason.
Counseling

Due to the fact that literature support for counseling specifically with the CD spouse is scarce, that which examines counseling with the elderly in general will be explored. Also, due to the fact that much of the aforementioned research sees CD spouses as “career caregivers” (Gladstone, 1995; Kaplan, 2001; Sidell, 1999), some caregiver counseling methods will be explored. Later, counseling implications as found in the literature in regards to specifically counseling the CD spouse will be examined.

As will also be seen in the examined literature, the older generations have proven to have many barriers to treatment. Therefore, the task has not been completed simply by getting the older adult/CD spouse to go to therapy; at that point, the complications may be just beginning.

Counseling with the older adult. Counseling with the older adult is a topic that has been explored by a few investigators. Research conducted by Burns (2008), found that counseling with this population is most beneficial when a client centered approach is used to foster a supportive environment where personal strengths, independence, and problem solving skills are a focus. Techniques such as validation, guidance, reflective listening, and empathy are equally important (Burns, 2008). Explored by Beckham and Giordano (1986) is the idea that behavioral techniques within therapy can also prove to be very beneficial to this population. By teaching the techniques, situational difficulties may not pose as much of a challenge to the CD spouse and some behavior-related hardship may be alleviated. For example, it is recommended that the therapist,

Encourage breaking behaviors into a series of tasks that can be accomplished from the least to the most difficult; allow clients to work on one problem at a time and experience small successes… [behavior techniques] can establish, re-establish, maintain, or eliminate
behaviors, and can be effectively used in conjunction with other therapies. (Beckham & Giordano, 1986, p. 261)

It is also suggested within the literature from Beckham and Giordano (1986) that the older adult is susceptible to change through the usage of many techniques. These proven effective techniques include, but are not limited to “cueing or prompting, reinforcement, modeling, corrective feedback, rehearsal, [and] relaxation techniques” (p. 261).

**Counseling with the caregiver.** Much of the aforementioned research deems CD spouses as “career caregivers” (Gladstone, 1995; Kaplan, 2001; Sidell, 1999). Therefore, some of the counseling methods utilized by practitioners and therapists can be applicable to this compilation of findings. Daire, Torres, and Edwards (2009) explored gender specific interventions for caregivers. In these findings, the male caregiver interventions are based around informational tactics as well as supporting the male caregiver in finding support services, whether they be community based groups, or individual treatment (Daire, Torres, & Edwards, 2009). On the other hand, the female caregiver interventions were slightly different. Counselors must “evaluate for and address the common occurrences for anxiety and depression” (p. 72); as well as, “focus on increasing health behaviors” and “help to increase social support” (p. 72). Later, they go on to discuss the need for a focus on building effective coping skills with caregivers in general, no matter the gender, noting that the common occurrence is to utilize emotion-focused coping skills, rather than the more effective problem-focused coping skills (Daire, Torres, & Edwards, 2009). Implications of the ineffective usage of emotion-focused coping skills are explored within this research. “Emotion-focused coping skills center on the caregiver’s internal strategies for managing emotional responses to external problems” (p.74). Emotion-focused coping skills become dysfunctional when emotions are regulated through the
use of denial, avoidance, or suppression of feelings. Kramer (2000) found that this way of coping breeds higher levels of caregiver distress.

As many researchers and clinicians focus on coping skills, some develop their own techniques to use with this population. Helen Hudson, a counselor, member of the American Counseling Association, and former caregiver, has six techniques that she uses with her caregiver clients. Patience, humility, a sense of humor, acceptance, persistence, and empathy are used in conjunction with her humanistic approach in order to meet her clients where they are and help guide them through their own processes (Shallcross, 2010). As with many other clinicians, she stresses the need for outside social support in addition to the individual and group therapy she provides; feeling from her own experience that “it was life giving for all of us to know that we were not alone” (Shallcross, 2010, p. 39). This adage is echoed in other research studies as well, finding that support groups increased caregivers’ perception of social support, normalization, and an experience of universality (Shallcross, 2010). However, although “support groups [can] be significant in reducing [caregiver] burden, …Zarit and Zarit concluded that individual and family counseling were more effective” (Harper & Lund, 1990, p. 242). Therefore, as research suggests, support groups are helpful in addition to individual or group therapy.

**Implications for counseling with CD spouses.** As aforementioned, a few studies have been conducted studying the effects of certain interventions for use with caregivers of those with dementia. Even less have been conducted taking into account that not all caregivers live with their spouse with dementia within the community. However, in the past few years, research has been conducted and has found that this specific population should get the therapeutic attention that it needs.
In Gaugler, et. al. (2008), caregivers were monitored throughout the process up to and shortly after the nursing home admission of their spouses with a dementia related illness. Their findings concluded that “comprehensive counseling and support can benefit spouse caregivers throughout [this] progression” (p. 425). They feel that nursing home admission should be a “transition” as opposed to an “endpoint” (p. 427). Furthermore, they go on to state:

guidance and support during [nursing home admission] may exert positive effects for dementia caregivers if offered as part of a long-term counseling program…long-term benefits that occurred after [nursing home admission]—and long after formal in-person counseling sessions had ended—are the result of the enhanced social support that the intervention produced. (p. 427)

**Toward clinicians.** The statistics for those who will most likely be experiencing dementia related illnesses within the next few years have been changing due to the rapidly growing prevalence of the illness. For example, “with expectations that the number of Americans age 65 and older experiencing dementia will grow to nearly 3 million by the year 2015 (U.S. General Accounting Office, 1998), mental health counselors will likely experience an increase in the number of clients who must address issues related to family caregiving” (Daire, Torres, & Edwards, 2009, p. 68). This statistic from 1998 is already slightly outdated according to the Alzheimer’s Association 2010 Report, which charted that already as of 2010, 5.3 million people have Alzheimer’s disease. Although the former statistical numbers were proven incorrect, these researchers were correct in stating that by 2015, there will be more caregivers who could use professional help. Implications for counseling this specific population are described within the literature.

First it is important to address that all CD spouses do not and will not have the same
needs. “Each [CD] wife has her own perception of herself and her situation” (Ade-Ridder & Kaplan, 1993, p. 14); therefore, the treatment for each should vary because they all “experience the caregiving role uniquely” (Daire, Torres, & Edwards, 2009, p. 78). Due to the fact that the population of CD caregivers is engaged in a relationship with someone with a dementia related illness, that dyadic relationship waxes and wanes with the ever changing qualities of the illness itself. As a result, the experience of the CD spouse will change consistently as well, creating an ever-changing role that can be examined and attended to through counseling (Ade-Ridder & Kaplan, 1993; Daire, Torres, & Edwards, 2009). It is also suggested in Kaplan (2001) that clinicians can address the ambiguity issue that CD spouses consistently undergo in accordance with the many role changes. The study finds that “clinicians could assist in labeling the ambiguity to help the caregiver cope with it” (p. 97). While there are some general categories in which CD spouses may share similar experiences, their feelings and emotions in regards to these topics may be different. For example, spouses may “want to talk about feelings of loneliness, loss of purpose, or unsettling or ambivalent feelings that they have around visits” (Gladstone, 1995, p. 511); however, in regards to these issues, says counselor Helen Hudson, “‘your client will be your greatest guide as to what [he/she] needs’” (Shallcross, 2010, p. 39).

Also, in addition to dealing with pressing issues in regards to the situation the CD spouse is a part of, “interventions aimed at assisting the continued personal growth and development of the spousal caregiver are necessary” (Ade-Ridder & Kaplan, 1993, p. 14).

**Toward institutions.** Implications for institutions and counseling CD spouses have also been presented within the literature. Gaugler et. al (2008) suggest that services offering support in all the stages before, during, and after institutionalization can be beneficial in working with any CD spouse of a LTC resident, not necessarily only those whose spouse is diagnosed with a
dementia related illness. Supporting the idea that the elderly put much emphasis and weight on the opinions of their doctors (Beckham & Giordano, 1986; Fersh, 1981), they suggest “physicians should make it a practice to refer caregivers not only to support groups, but also to individual and family counseling” (Gaugler et al., 2008, p. 427). Likewise, findings from the Tornatore & Grant (2002) study suggest that “more services aimed at relieving caregiver burden after nursing home placement may be warranted” (p. 505). It is also identified within the literature that nursing homes tend to cater to the individual who resides within the facility, as opposed to the CD spouse. Due to this, the research suggests:

Nursing homes and other institutional settings often regard families as obstacles, rather than finding a way to include them in an overall plan of care. Effective integration of families within these settings would have positive results for everyone involved: family caregiver, nursing home staff, and the patient. Approaches to including the family in meaningful ways would underscore the fact that long-term care is personal and social as well as medical. (Zarit & Whitlatch, 1993, p. 36)

**Barriers and challenges to therapy.** There are many reasons why there would be barriers and challenges to therapy. Some of these factors are explored by the examined literature.

**Impact of others.** While there are some models in place for usage in the therapeutic setting, there are also barriers to getting the CD spouse to actually go to therapy and challenges that are faced once it has started. These challenges can manifest as predisposed ideals and social mores, issues of pride, family influences, monetary difficulties, etc. Another barrier is the double bind that many people in this situation put themselves in unknowingly. Those in this age group, as aforementioned, do not like to complain about health or relationship issues due to
social stigmas and others’ perceptions of them. Unfortunately, this can result in an attempt to minimize their difficulties in an effort to hide them from others (Burns, 2008). The double bind that is created in this situation is that reaching out and finding social support has been found through previously mentioned research to be a coping skill when dealing with this situation. When, the CD spouse experiences more difficulty in coping with the challenges that they face, refuse to talk about it, and therefore, keep cycling in a pattern of denial in order to keep going, they become figuratively stuck. This can impact the sense of identity and alter the sense of self worth. It is likely that social context, as expressed in the reactions of others, will impact upon his/her sense of identity (Kitwood, 1997). For a person with a spouse diagnosed with a disease that slowly wears away the previous identity and roles of the individuals and couple as a unit, the possibility of removing their identity in a social network may be too much to physically, mentally, and emotionally handle. Therefore, treatment is avoided.

*Fear of the unknown.* The idea of therapy also addresses coming to terms with and acknowledging the unknown. This unknowing can evoke fear, yet also a concept of responsibility. If the unknown becomes known, it cannot be hidden and denied-someone must take responsibility for it. To avoid responsibility can also impact self esteem. It can be seen as a fault for denying the problem and causing stress in the spousal relationship. In many cases, the healthy spouse rejects the idea of therapy for this reason (Beckham & Giordano, 1986; Robinson, Clare, & Evans, 2005).

*The therapist.* Another type of barrier to treatment, concerns the therapist. In much of the research done concerning this topic, there are implications that the therapist should be flexible and open-minded (Beckham & Giordano, 1986; Wolinsky, 1990). Also, it is important to note the role that topics such as ageism and countertransference play in the therapeutic
relationship. As found in the research reviewed, many elderly clients have reservations about seeing a therapist in general, and adding to the unease of talking about problems and hardships to a third party, is the idea that this helper may not have any real life experience if he/she is young. Therefore, the idea of reverse ageism comes into play as seen through the eyes of the elder clients. For example, Beckham and Giordano (1986) cite that therapy may be easier for them “… if the ‘helper’ has also lived a number of years, at least into middle age” (Buckley as cited in Beckham & Giordano, 1986, p. 260). Furthermore, the CD spouse may encounter a therapist dealing with issues of countertransference because of the prevalence within today’s culture concerning dementia related illnesses and/or spouses living separately due to a LTC admittance. Also, due to his/her own bias, the therapist may dismiss the problems as “meaningless” (Beckham & Giordano, 1986, p. 260) problems of older age. He/she may also see the mental process of his/her client declining, aggravating his/her own fears, feelings, ideas, and/or perceptions of getting older (Wolinsky, 1990). Therefore, even though the community dwelling spouse may have made the initial attempt to go to therapy, once in the therapeutic relationship, there still may be barriers and challenges to treatment.

**Dance/movement Therapy**

**Dance/movement therapy defined.** Dance/movement therapy (DMT), according to the American Dance Therapy Association, is “the psychotherapeutic use of movement to promote emotional, cognitive, physical, and social integration of individuals” (American Dance Therapy Association, 2009). Further, the practice of dance/movement therapy is about “helping individuals--those who are generally healthy, as well as those with mental illnesses and physical or mental disabilities--to regain a sense of wholeness by experiencing the fundamental unity of body, mind, and spirit…[this], is the ultimate goal” (Levy, 2005, p. 1). According to Gladding
(1992), DMT serves the purpose of creating a “whole” individual by working within the Gestalt therapy ideals of including physical, psychological, and social aspects of one’s being (p. 29). It “free[s] people to move in ways that talk alone does not allow” (p. 37). Gladding feels that “the main emphasis of any movement or dance should be on improving participants’ self-esteem, physical well-being, and sense of accomplishment” (p. 33). To accomplish this task he describes in detail the ways in which the above three aspects can be explored. He states,

physical goals may include releasing physical tension through activities and broadening one’s movement repertoire. Psychological goals might be to channel one’s self-expression in a meaningful way and to help a client adjust to reality. Social goals may be to get a client to join a group interaction and to develop social relationships with others.

(Gladding, 1985, p. 10)

**DMT with the elderly.** Fersh (1981) adds, through DMT, elders “may derive a feeling of aliveness and vitality through spontaneous movement expressions. Isolation may be reduced, while self-esteem and self confidence are nurtured” (p. 23). Marcia Spindell, executive director of the Expressive Therapies Center in Providence, RI, takes this idea one step further and explains the positive effects of the feelings of this new way of connectedness with others. Her belief is that these feelings can increase the sense of integrity that is so vital to this age group and reaffirm the sense of control they can still achieve relative to their actions and feelings (Spindell, 1996).

Specific to this population is physically debilitating tension, and as “Henry Stark Sullivan … points out, dance therapy can provide an outlet for relieving tension and building support systems to deal with later life stressors” (Levy, 2005, p. 229). Many of these “later life stressors,” as detailed in the literature above, can manifest as or relate to decreased body
awareness, physical pain, anxiety and depression.

**Addressing physical issues.** It is a main principle within the practice of DMT that the mind and body are connected. Also, it is a normalized fact of life that the body’s own healing process slows as age increases. Furthermore, “as we grow older, more effort is required for the body to return to normal after periods of stress and exertion” (DeVries as cited in Fersh, 1981, p. 23). Therefore, for a population in which physical pain and discomfort is frequently experienced, DMT is a way to address these issues. According to Fersh (1981), DMT may “offer some corrective measures in structural body alignment and alleviate the pain of stress points where chronic tension and improper weight distribution have been concentrated” (p. 23).

It is believed by some that benefits in regards to the physical self “will give rise to parallel benefits on the social and psychological levels” (Levy, 2005, p. 229). Later, Levy addresses somatic exploration of tensions including that the use of “relaxation techniques to release psychophysical tensions [is] also emphasized” (p. 229), along with other methods including calisthenics, progressive relaxation, and yoga.

**Addressing psychological issues.** As seen in the literature, DMT helps to forge a connection with the outside world when depression or psychological hardship has turned a person inward. Dance/movement therapy can “provide both an enjoyable escape and a source of interpersonal contact” (Ritter & Low, 1996, p. 251). In addition to many other benefits “DMT helps to achieve meaningful interaction with others, increase self-esteem, and promote self-expression, and can alleviate depression” (Hoban, 2000, para.4). As previously mentioned, those in this specific age population can be opposed to expressing their inner feelings in an outward manner; however, as Gladding (1992) describes, DMT “is especially effective with people who are closed to talking about their feelings” (p. 29) due to the integrative nature of the work in and
of itself.

Although not specifically studying the effects of DMT, Cooper et. al (2007) executed research reviewing interventions combating anxiety as found in dementia caregivers. They found that “the only interventions reported as effective…were caregiver groups involving yoga and relaxation, and the only [group] to report a significant reduction in anxiety was also the only one to include relaxation and CBT targeted at anxiety” (p. 187). These findings prove that with counseling techniques aimed at specific goals, and coupled with relaxation or other somatic techniques, positive results can be found.

**DMT with the CD spouse.** Although there is much literature based on DMT with the elderly, there is presently no literature on utilizing DMT specifically with CD spouses. Community dwelling spouses have recently come into the view of researchers in the form of benefits of counseling, as there is a small amount of literature pertaining to treatment of this growing population. However, the literature regarding specific modalities for treating the issues of these spouses remains to be seen. Gladding touches on the benefits of DMT with women in regards to their caretaking nature stating, “through [DMT] [women] come to a clearer understanding of their own boundaries and are thus able to be more caring for themselves” (Meyer as cited in Gladding, 1992, p. 33). Also, as seen in Fersh (1981), DMT “can broaden and deepen self-awareness and aid in developing a realistic body image, thus providing a physical basis for identity” (p. 23). In accordance with the issues that CD spouses deal with when trying to find the balance between caring for self and other, previously examined literature contains themes of declining physical and psychological health of caregivers when caring for the spouse with the dementia related illness. These themes emphasize the need for the potential positive benefits of DMT with this specific population.
**DMT techniques.** The literature reviewed places much emphasis on the themes of combating social isolation, depression, anxiety, and role ambiguity, with ideas of connectedness on an interpersonal level. Also, there is much emphasis on the fact that this age group may have many barriers to treatment. While there are many DMT techniques that can address these issues, a few which have been examined in studies are explored here.

**Mirroring.** According to Fersh (1981), the mirroring process begins with the therapist and the client as an individual, where the therapist may reflect the movement behavior of an individual, internalizing their movement repertoire as much as possible. This technique serves to help build a relationship of acceptance and trust. It may communicate to the older person that someone is able to empathize with them, thus relieving a common feeling of isolation. (p. 24)

The concept of mirroring is further described as “not mimicry, [it] entails making contact with what a client is experiencing on a visual and kinesthetic level and then communicating it back with equivalent muscular activity and affect” (Shustik & Thompson as cited in Erenberg, 2007, p. 16). In this way, the client can build a relationship with the therapist and be able to learn ways of communicating with another individual through movement. After this, a client can learn to implement these learned tools of mirroring within a group setting. In this way, relating to others and increasing the feelings of identity, feeling understood, and self worth can manifest (Fersh, 1981; Hoban, 2000; Spindell, 1996). Lastly, it may combat some of the possible ageist feelings that the older client may possess by feeling understood.

**Breathwork.** The positive effects and benefits of breathwork are vast and can span almost every population. However, for the purposes of this review, breathwork that aims to address the aforementioned issues will be examined. As stated in Fersh (1981) with regards to anxiety
issues, “the therapist may use breathing and relaxation techniques. These methods help establish the emotional readiness to confront the cause of distress” (p. 30). Also breathwork breeds relaxation and according to DMT pioneer, Alma Hawkins, “relaxation [is] a highly significant factor affecting perception” (Levy, 2005, p. 74). Many of the above issues deal with the perceptions of the CD spouse and his/her own particular situation; therefore, techniques that involve relaxation and breathing may be very effective. In addition, breathwork can help to alleviate tensions within the body that may be caused by stressful events and issues, as well as, connecting one’s inner self to the outer world in a non-confrontational way (Bartenieff, 2002; Hackney, 2002).

**Dance as Self Therapy.** Of the several resources available in regards to dance as self therapy, one most succinctly describes a connection to the situation faced by the community dwelling spouse. Janet Carlson, author of a book about partner dancing as self therapy, states, “You need to be in control of yourself, your body and your emotions, without succumbing to the temptations to try and control your partner, or to be in charge of the ‘us’ as it moves” (Carlson as cited in Wilson, 2008, para. 5). This quote emphasizes the need for the CD spouses to be able to understand themselves and the need to identify his/her role in the relationship with the spouse residing in LTC.

As seen in the above review, there is much information in regards to counseling with the elderly and the caregiver, as well as DMT with the elderly. However, there is limited research based on the experience of the CD spouse. Recently, the state of the research has changed significantly to include implications for work with this sub population. These implications are relevant to the purpose of the present study. In conducting this clinical case study group, I propose to answer the question: How can DMT offer support to and aid in the treatment of CD
spouses of residents in LTC diagnosed with a dementia related illness? As seen in the above literature support, there is a gap that should be filled in order to serve a population in need. Through looking at the ways in which counseling is applied to the population of caregivers within the home, as well as the elderly in general, many connections can be made in order to extend the treatment towards the CD spouses. As far as the area of DMT is concerned, there has yet to be documented research on this topic; however, by utilizing the concepts and ideals of DMT, this study is the first of its kind. It will provide a deeper look into the lives of two women who are CD spouses of very different cases of dementia related illness. It can serve to be a starting point for larger studies that require more in depth research to forward the field and shed light on an underserved population. Longitudinal studies can be used to examine the effects of DMT from the point of the spouse’s diagnosis, through institutionalization, during the passing of the spouse, and later as a bereavement tool.

In the following chapter, the methods and procedures that were utilized to execute this clinical case study will be described. Details are given and ethical considerations are explored as warranted by the site Internal Review Board in order to protect the clients.
Chapter III: Methods and Procedures

Methodology

This study was conducted utilizing the clinical case study method. This qualitative style is rooted in “studying people in real life situations… and [striving] to probe the substance and meaning of the human experience” (Berroll, 2004, p. 210). Due to the fact that a need was found with a subpopulation that was proving to be underserved, a clinical case study was employed in order to conduct and present the research. Coupled with a humanistic, person centered approach, utilizing this method would illuminate the intricacies of the problem and capture the subject matter as it changed on a weekly basis. The clinical case study employs a more in depth examination, rather than an overarching viewpoint. As stated in Chaiklin and Chaiklin (2004), the clinical case study has a “richness [that] allows a focus on understanding the situation. No other research method allows simultaneously seeing the whole and the parts…” (p. 72-73). Interventions derived from a person centered approach can be best employed within a qualitative case study due to the flexible nature of this method. In order to explain how dance/movement therapy could be a supportive counseling tool for CD spouses of LTC residents diagnosed with a dementia related illness, for the purposes of this study, a method that could allow the deep examination of effects over a period of sessions needed to be employed.

Theoretical Framework

Qualitative research within clinical case studies is conducted within a therapeutic context. Therefore, it is important to note the theoretical framework(s), from which the clinician/researcher is working. While I, as clinician and researcher, utilize many different theories within my work and practice, I am aware that the frameworks that I am most influenced by are the humanistic approach to therapy, specifically, client centered therapy and a mixture of
the ideals and concepts of dance/movement therapy pioneers, Alma Hawkins and Marian Chace. The usage of the humanistic framework within a qualitative method works to more deeply examine the actualized experience of the participants (Berroll, 2004). The ideals and principles inherent in the work of dance/movement therapists, Marian Chace and Alma Hawkins also emphasize a client centered approach. Hawkins was herself influenced by humanistic psychology and believed that “growth happens in time with the client setting the pace for his or her own insights” (Levy, 2005, p. 75). Also, Marian Chace was able to foster the experience of her clients through her ability to guide them in the group process (Levy, 2005). These two dance/movement therapy frameworks work together with humanistic psychology in many ways. First, the Chacian method evokes subjects, themes, and directions of the group from the client. In utilizing these concepts, a therapist employing the Chacian method can help to foster that which the clients are presenting; thus, complementing the ideals of the humanistic approach. Carl Rogers’ humanistic theory derives from a person centered place. The therapist starts where the client is, much like someone employing the Chacian and Hawkins’ methods. His three conditions for therapeutic growth include unconditional positive regard, empathy, and congruence. These aspects of the Rogerian therapeutic process encourage the therapist to put the needs of the client first and to proceed at the rate in which the client is comfortable. All three theories work well within the moment and evoke an experience rooted in the present time (Ivey, D’Andrea, Ivey, & Simek-Morgan 2007; Levy, 2005) that can cater to an organically evolving process. Due to this aspect, these theories also tend to lean on the more improvisational side of therapy. There is a structure, yet it is not very demanding and the boundaries are not necessarily fixed; there is room for adjustment, change, and growth. These three frameworks help to support the reasoning for the needs-based treatment plan approach; resulting in the creation of over-arching goals for the
sessions but being able to follow the clients in their issues and tribulations of the day.

**Participants**

Participants of the case study included two Caucasian women between 70 and 90 years old who met the established requirements. The inclusionary requirements entailed that the participant be a CD spouse of a resident who had been diagnosed with a dementia related illness and was residing in the LTC site. Both women had a spouse that had been residing within the facility for at least 2 years. One of the resident spouses was diagnosed with Alzheimer’s disease and had been residing on the Alzheimer’s special care unit for 2 years. The other spouse recently made a transition from early stage dementia on a higher functioning floor to a more care-based floor and also was placed in a Geri-chair instead of a wheelchair. Due to the fact that the transition into the Geri-chair marked a change in the experience of the CD spouse, it will be discussed further in Chapter IV.

Exclusionary variables included lack of transportation to the site for the duration of the study, being in poor physical health, and not being available during the time and dates of the group sessions. All possible potential participants were given a letter (see appendix B) by other creative arts therapists at the site and/or this clinician/researcher. This letter was the same for all possible participants to ensure equality in explanation. Potential group members would have researcher contact information in the letter if they chose to be a participant. Flyers (see appendix C) with a brief explanation of the group were hung up in the site elevators, displayed at the front desk by the visitor sign-in sheets, and on various bulletin boards throughout the building for visiting spouses to see. If a spouse was interested in taking part in the group, the contact information provided on the flyer would direct them to either the Creative Arts Therapy Department to obtain the contact information for the researcher, or to the researcher herself. The
recruitment process lasted two weeks and by the end, had established a group of four female spouses. However, prior to the start of the first group, two of the participants opted out. The remaining two spouses were taken through a process of explanation and informed consent, administered by the clinician/researcher (see appendix D). These participants were also administered the Relative Stress Scale (RSS) (see appendix E) which was also administered at the end of the group.

**Measurement Tools**

The RSS was originally developed and used in a study in 1982 by Greene, Smith, Gardiner, and Timbury. The study was developed in order to measure the psychosocial, emotional, and mental stress on caregivers of those with dementia. It is comprised of a 15 item questionnaire with answer columns and includes a point score: “0= never/not at all; 1= rarely/a little; 2= sometimes/moderately; 3=frequently/quite a lot; 4= always” (Thommessen et al., 2002, p. 79). Also, “the items from the [RSS] can be summarized into three categories; ‘Personal distress’ experienced by the relatives in relation to the patients, ‘Life upset’ resulting from having to care for the elderly, and ‘Negative feelings’ toward the elderly person” (Thommessen et al., 2002, p. 80). The RSS was used in this study because it allowed for qualitative findings if used as a questionnaire instead of solely collecting numeric scores. Using the tool as a questionnaire led to open discussion and topics of conversation because it evoked personal feelings as opposed to numerical values. Also, by omitting the scoring numbers from the tool before it was given, those completing the tool might not struggle with quantifying their feelings. The categories of personal distress, life upset, and negative feelings are personal in nature and might be difficult to quantify. It was also considered relatively easy to understand by the IRB at the site where the research was conducted. Also, a treatment plan could be built based on the
answers given in the pre-test. Depending on those answers, goals and objectives could be formatted for use within the sessions and tailored specifically to the needs of the clients. The original over-arching goals were based on assumptions from the previous literature; however, the results of the RSS pre-test specified the exact areas in which these two particular clients needed support, and the treatment goals were adjusted for that purpose. Normally, the test is scored for usage with quantitative findings; however, for the purpose of this study, the findings will be discussed in a qualitative manner, with no statistical evaluation of the scores.

The second tool that was used was a movement coding sheet. This coding sheet was developed by the researcher and utilizes aspects of Laban Movement Analysis (LMA) and the Kestenberg Movement Profile (KMP). The coding sheet was filled out by the researcher at the initial meeting and was used in the further development of the treatment plan for both of the participants. A separate pre-test-coding sheet was filled out for each participant as well as a post-test coding sheet after the sessions were finished in the sixth week.

**Procedure**

After the pre-test was completed during the first week, a treatment plan complete with goals for therapy was created. Due to the assessment/needs based treatment plan, there would not be a specific detailed account of what would be done during the sessions prior to the assessment being administered. This is due to the fact that there could not have been a generalization made concerning what the individuals’ presenting concerns would be. This can be supported by the findings in Daire, Torres, & Edwards (2009), which call for an individualized approach to counseling, stating, “the population of …caregivers is very diverse, with each member experiencing the role differently” (p. 78).

Although there were over-arching goals for the sessions, the interventions evolved
organically related to the issues of the present moment. The clients progressed at their own pace, while the researcher served as a guide in the process. The DMT sessions included verbal/non verbal communication, movement interventions, and verbal processing. Each session was held in the Creative Arts Therapy studio at the LTC site with the door shut for complete privacy. A string of yarn was laid in a circle on the floor around the chairs of the participants prior to the start of each group to act as a boundary in order to keep the space feeling safe and create a physical and figurative sense of belonging. There was also soft music (jazz piano) playing to ensure a welcoming atmosphere. Participants were reminded at the beginning of each session that taking breaks was permitted if they were feeling tired to ensure their safety. This reminder was repeated each week in order to prohibit over exertion from coming into play and perhaps influencing possible outcomes. Each 45 minute session was recorded via progress notes which included direct quotes from the participants, mini movement profiles, and researcher observations, as well as clinical documentation of the happenings during the course of the sessions in the form of DIRP notes and therapeutic progress reports. After each session, the researcher journaled in order to address issues, if any, that might have hindered the study (i.e., transference, personal opinions, questions) as well as to inform the researcher of the overarching direction for the next session. At the conclusion of the six weeks, a post-test of the RSS was administered to the participants by the researcher for the final collection of data. The findings from this data will be described in detail later in Chapter IV.

It is important to note that due to a spousal hospitalization, the fifth week of sessions was cancelled. Although the exclusionary requirements mandated that the participants must be present at every session, this was an occurrence that could not be avoided. Sessions recommenced the following week for the last session. Implications of this incident will be
discussed further in Chapter IV and V.

**Data Analysis**

The data collected was in the form of pre and post tests, movement profiles, DIRP and progress notes, direct quotations, and researcher observations. The pre and post test results were compared to find the change (if any) within the answers over the six week period. Movement profiles, researcher observations, direct participant quotations, and progress note findings were compared to the originally established treatment plan and over arching goals in order to see the change (if any). The data was analyzed by reading and re-reading the findings in order to extract any emerging themes and to ensure full exploration of the information. Also, highlighting and color coding was used in order to keep the data pertaining to the two participants separate. A third color was used to highlight similarities in the findings. All of the forms of data that were collected were analyzed, as a case study calls for a holistic view of the findings.

The RSS pre-test answers reflected the CD spouses’ perception of the psychosocial effects of having their spouses in LTC. This was used in order to gain information for use within the treatment plan, as well as to gain insight as to the mindset of the CD spouses. Progress notes of the sessions were carefully examined to find any inconsistencies or similarities between the answers to the RSS, the observations of the clinician, and the direct quotes of the clients. These answers were also compared to the findings of the movement profiles that were completed for each client. In effect, the somewhat linear path of data analysis started with the answers to the RSS pre-test as related to the treatment plan. These findings were then compared to the movement profiles and direct quotes of the clients, as well as the clinical observations/notes of the sessions. Finally, the results of the post-test RSS were introduced to the comparison in order to relate the end results to the beginning goals. After this data was examined in a linear pattern,
it was analyzed in reverse. The end results were compared to the findings at the beginning of the group in order to analyze for change in spousal perception of effects/stress on self, as well as change (if any) observed by the clinician. The findings of the data analysis were then grouped together in terms of needs, goals, interventions, and observed/stated change (if any). The results of this analysis will be later examined in the following chapters.

**Ethical Considerations**

In accordance with the site IRB’s requirements, the following ethical considerations were taken into account. In order to keep the confidentiality of the participants, real names will not be used and identifying data will not be published. The RSS test results and session notes, including but not limited to DIRP notes and therapeutic progress notes, will be destroyed after the full completion of the study. The formal and informal personal notes compiled by the researcher have been kept secured via password protection in locked files on a personal computer. Due to the nature of group processing, ultimate confidentiality could not be strictly guaranteed. It is impossible to restrict the actions of participants while outside the perimeters of the group. However, participants signed their promise that privacy be maintained: what would happen during the group, would stay within the group. Simply signing on this aspect helped to create a level of trust and safety within the group, as evidenced by the participants’ willingness to self disclose. Participants were informed of the risks, which due to the nature of the case study, were minimal not exceeding the risk inherent in the regular scheduled programming and creative arts therapy groups at the site. Also, as per the nature of DMT, the risks of this study would not exceed the risks associated with regular exercise and everyday movement. The spouses were also informed of the benefits including, but not limited to, a possible new awareness of the spousal relationship, a possible new awareness of the effects of emotional stress.
on the body, developing coping skills and strategies that can help in times of stress, a possible reciprocal validation of feelings through being a group member along with other spouses, and/or making connections with other people in a similar situation and learning that one can support others through the process and vice versa.
Chapter IV: Description of Clients/Sessions & Results

This study set out to explore how dance/movement therapy could be a supportive counseling tool for use with CD spouses of LTC residents who had been diagnosed with a dementia related illness. Distinct from much of the published literature concerning this topic and those with close similarities, a clinical case study approach was used. As a result of this methodology, a deeper understanding of two specific cases was cultivated. In addition to the notes and observations of the researcher, as well as direct quotations from the participants, a pre- and post-test was administered to determine the amount of change, if any, and to provide the basis for the six week session treatment plan.

Preparation

After the informed consent was given and participants were ready, the six weeks of 45 minute sessions began. Each participant filled out the 15 item RSS and was given a few minutes to go to the bathroom or get comfortable after completion. One participant chose to momentarily leave and the other stayed in the room. During the break, this researcher moved the tables out of the way and took a glance at the RSS results. Due to the fact that the RSS was given just prior to the start of the first session, I had already decided that the first session would involve interventions based on what the women were presenting with, simple breath work to get them used to paying attention to their bodies, and anything that was seen as an extremely pressing issue after looking at each completed RSS. As I did not have time to analyze the scale findings in detail, I scanned them, specifically looking for any check marks in the always column. Upon seeing high marks within the first few questions, as well as in the Is your sleep interrupted? question and Do you feel that you need a break? I added these to my previously planned ideas for the session.
Description of Sessions

**Session one.** The first session began with a dialogue and formal statements required by the IRB, as well as normal protocol for dance/movement therapists. I assured the women of the time the group would be ending in order to establish boundaries; the fact that if they needed to take a break at any time they could and simply join again when they felt ready (to promote safety and personal insight into limitations). I also assured them that there was no right or wrong movement in the non-judging atmosphere of the group. This last comment was intended to help the women feel more at ease with moving authentically and removing a possible critical, self-defeating component from the process.

I began with exploring breath and assisting the women in attuning to their own breath patterns with an observational view, noticing if their breath was shallow or deep, fast or slow, even or uneven. I emphasized the support of the chair so that they could let themselves relax into it and be fully present in the exercise. I used some of their own words to help them relax and release with a more personal touch. For example, client one, who will be called *D*, entered the room with an exhausted tone expressing everything that she had had to accomplish that day in regards to everyone in her family. Therefore, during this breathing intervention, I offered, “The chair is there to hold you up, you don’t have to hold up anything right now, not even yourself.” As a result, both women exhaled even deeper and sank farther into their chairs. I then started a full bodied breathing intervention, starting from the feet and moving upwards to the head. I chose this direction because the women were so focused on thinking, I wanted to let them turn their attentions toward their body instead of everything else going on for them at the moment.

After the breathing intervention, the women started to process aloud. *D* stated, “my mind
races” and expressed that when she falls asleep, she doesn’t stay asleep. Client two, who will be called P, expressed that she finds pleasure in breathing techniques, as she does yoga and hypnosis. She also stated, “I eat my feelings.” Then, grabbing her stomach said, “This is how I deal with things.” With this, D nodded in agreement, stating “I manage.” With these words both women began to express all of the things in their lives that they were managing at the moment. There were many recent changes in both situations; and interestingly, the situations had many similarities. Both women expressed financial difficulties due to bills related to LTC, as well as the financial needs of their children. P’s adult child recently moved into her home in order to relieve some financial pressure from both herself and her mother; and due to the economy, one of D’s children recently was in financial hardship as well. Both women expressed that they were consistently “taking care” of someone. At this D said, “I just can’t give any more money, time, and energy…there’s nothing left” and P nodded in agreement.

I asked, “What is one thing you don’t have to manage?” P shrugged her shoulders in a gesture of uncertainty, while D automatically felt that her self-maintenance/pampering rituals were of importance in this way. She also very strongly announced that her garbage disposal is the one thing that she wants and “needs” to work every time.

Session one ended with my suggestion to, throughout the week, note what aspects of their lives do not need their management in order to work efficiently. With this both women nodded and we held hands to perform a short breathing ritual before ending the group.

**My observations of session one.** It was clear to me that while these women had many similarities, there were many differences as well. For example, P presented as very calm and relaxed from the outside, though her body is what gave her trouble. D, on the other hand, presented as anxious and directed her attention in many different directions; it was her mind that
gave her trouble. Due to the fact that both of these women had so many complications in their lives, it was easy to sit and simply vent the problems to the group. Although there are positive effects to cathartic venting, there can be more benefits from exploring pressing issues. After session one, I realized that as the group leader, I would have to consistently bring the tangential thoughts back towards the focus of the group. This would most likely require a firm but gentle approach as the group was new and I wanted to build trust within the therapeutic relationship, yet I did not want to insult the women or have them feel like I was verbally cutting them off.

I also think it is important to note here the physical differences in the two CD spousal caregiving roles. D’s husband had recently undergone a change to a lower floor where there is more hands-on nursing care. He was also switched from a wheelchair, into a G-chair. The Geri-chair, or G chair as it is known, is more supportive than a wheelchair. However, the move to a G chair is oftentimes an acknowledgment of a decrease in physical ability of the resident due to the fact that a large G chair is not a self propelling piece of equipment. The person using the G chair becomes dependent upon someone else to help them mobilize from place to place. Although D’s husband was decreasing physically, according to D, his level of dementia had not changed much. On the other hand, P’s husband was in fair physical condition, he propelled himself in a wheelchair, yet he resided within the Alzheimer’s Special Care unit. He did not always remember who she was, and she expressed sadness around this topic. This is P’s second marriage, and although she would express happiness in regards to the 15 years they spent together, she expressed frustration that the disease had “robbed her” of the “golden years.”

Another observation that is important to note is that P had experience being a peer counselor and co-group leader. At the time of the study, she was also involved in a peer support group run by herself and a social worker. During the first session of this study, I noticed P
asking leading questions of D and somewhat taking on a leading role. While I was able to maintain my leadership during the group, this is something that had to be kept in mind. She may have been slipping into that role due to habit, to take focus off of herself, or to help control someone else’s situation because she felt a lack of control in her own situation. There were many possibilities; however, after only the first session, it was important to simply acknowledge the circumstance.

**Preliminary movement observations of D.** The moment that D walked through the door it was obvious that she had a lot going on. She stepped over the threshold of the door and breathed a deep exhale and sighed. Her shoulders sunk downward momentarily and then she picked everything back up with a breath and abruptly stepped towards an open seat. D presented with a sinking torso, an upper lower disconnect, passive lower body weight, and enclosing shoulders. Her eyes, however, were consistently moving around in an indirect fashion. She would focus intently when someone was speaking, but would revert back to looking at her nails, her rings, her feet, her purse, the room, etc. It seemed as if she was constantly “checking on” or “fixing” everything around her. Her breath patterns were shallow and she moved within far and near reach space. She expressed either large scale gestures or very small ones and presented a tired affect (droopy eyelids, sinking cheeks, head tilted downward). She seemed to have an affinity for movement within the horizontal plane and would make circles with her hands in an outwards fashion as she spoke, as if generating something.

**Preliminary movement observations of P.** Like D, P also presented with a sinking torso; however, P presented with a core/distal disconnect. She expressed weighted gestures with her arms or legs, and very rarely attended to her core. She similarly had shallow breath patterns, unless consciously attending to her breath. She generally utilized near reach space and
commonly sat with her hands resting in her lap, demonstrating passive weight throughout her body. Her jawline was very bound and her chin was tilted slightly upward as she spoke. Her affect also presented as tired (droopy eyelids, loose eyebrows, downward gaze). She seemed to have an affinity for the vertical plane, yet there seemed to be more sinking than rising. She spoke softly and very rarely gestured when she spoke. She seemed to fade into the background unless she was speaking, and even then, there was very little weight within her voice when she spoke about herself or her current situation.

**Treatment plan.** There is some literature based on the effects of placing a spouse with a dementia related illness in LTC on a CD spouse. However, due to the fact that I was unsure of the effects on these two specific spouses, a treatment plan was established after the first session. This way, my observations, client responses/reactions, direct quotes, and answers to the pre-test could all be the basis for the development of specific goals within a treatment plan to be used during the course of the sessions.
### Treatment Plan

**Goal: Reduce levels and symptoms of anxiety**

**Objective I:** Develop coping skills and modulate physical manifestations

**Interventions:**
1. Relaxation techniques (experiencing and learning)
2. Imagery
3. Breath work (experiencing and learning)
4. Education

**Goal: Reduce symptoms of depression**

**Objective I:** Modulate body posture

**Interventions:**
1. Utilize movement that opens and lifts the body (BESS)
2. Increase usage of breath support

**Objective II:** Increase self esteem and self efficacy

**Interventions:**
1. Create opportunities for awareness of possible self growth
2. Create opportunities for success/feelings of mastery
3. Encourage usage of positive self statements

**Goal: Find balance between caring for self and other**

**Objective I:** Create mind/body awareness through physical distinction between self and other, as well as insight into the ability to stay with oneself while being with another

**Interventions:**
1. Explore vertical plane/near reach space for “self”
2. Explore horizontal plane/far reach space for “other”
3. Explore mid reach space for modulation between the two (1+2)
4. Find and exercise usage of Core Distal connection with breath support
Session two. The second session started with a circle of yarn on the floor enclosing the chairs for the group. Also, as the women entered the room, there was soothing, calm music playing to set the tone for the environment. The plan for this group was to encourage relaxation, explore different aspects of space (near, mid, and far reach), and concurrently explore core-distal connectivities in order to relate to self and environment while modulating through the middle. I had hoped that this would lead to building coping skills in order to stay true to oneself while caring for others, not simply one or the other.

This group began with an announcement from D. With a seemingly proud vertical lift in her chest, as well as a widening of her shoulders and bright affect, she expressed that she hadn’t had a good night’s rest in years and in regards to the last session stated, “I was in shock that it worked! I did the breathing and fell right asleep…and STAYED asleep!” She was very happy and relieved that something “finally worked.” At this, P encouraged D to try and remember a time when she could sleep. D thought for a moment and expressed that it was most likely long ago when her children were somewhat grown, before she took in her ailing father. She expressed this with a nodding head gesture, and after completing her thought quietly acknowledged the caretaking connection with, “oh.”

After the opening dialogue and warm-up, near reach space became the first intervention with a focus on one’s self, or core. D stayed within near reach space and made generating outward movements with her upper limbs. P utilized very close near reach space and used touch as a means of body sensing and exploring. I suggested that eyes could be closed or open as both women were seemingly slightly hesitant. At this, both women closed their eyes and were able to move freely and authentically. Their movements became more free and less hesitant.

Mid reach space brought very interesting results. Both women had trouble here as
evidenced by change in movement qualities and an aspect of possible conscious “trying” in regards to their movement. For example, movements that were previously even and free flowing, now became consistently adjusted; the smoothness of the movement was gone. Also, both women tilted their heads towards their movement with furrowed brows, instead of letting their body move. They seemed to be intently concentrating.

Far reach space with a focus on the outer environment was the next offered intervention. Far reach space brought an increase in kinespheric usage for both women and almost a sigh of relief from D. D accelerated in time and began to tilt forward in her chair so much that her connection to her core lapsed and she had to catch herself on her chair arm so she would not fall. She also became more indirect, attending to all the space area that she could reach. It is important to note here that P did not fully engage in far reach space as she was ailing from a pulled neck muscle and could not completely extend her arms, so she opted to remain mindful during the processes that she could not outwardly, physically experience.

When the experiential aspect of the group was ended, D verbalized immediately in response to my question regarding the experience. She said, “I could feel the difference between the near and far, but I forgot about the middle already.” I nodded, and D began to process aloud and at a very quickened pace. She immediately began a free flow list of tasks and anxieties in her daily life that exhaust her; this was coupled with a quick darting of her eyes and hands. When she stopped to take a deep exhale and retreat back into her chair, I asked her, “would it be fair to say you spread yourself pretty thin?” She nodded immediately in a “yes” gesture and wide eyes stating, “oh, yes.” She then said, “I guess it’s affecting me more than I thought.” P nodded in an agreeing gesture and said, “I know exactly what you’re saying.” In regards to her experience P, on the other hand, spoke of her near reach space as very informative. She said she
loved exploring her body that close, expressing that she was “taking her time” with it. However, because she did not get to explore her mid or far reach space, she felt that she could not comment on it. Although, when asked how she feels about her relationship to her far reach space and that which is around her, she expressed sadness in regards to her daughter. As she said this she retreated in her torso, put her hands tightly in between her knees, and expressed, “I’m always saying, I’m keeping my mouth shut.” She then expressed that she had nothing more to say. With that, I encouraged the women to pay attention to the ways in which they modulate between caring for self and other as the week progressed. I encouraged them to take time for themselves, as well as give time to others; however, to keep a mindful awareness of themselves while caretaking. They both nodded and D said, “I can try that.” The group was ended with the holding of hands and a breathing ritual to end the group on a slow, relaxed note.

My observations of session two. First and foremost, through a movement lens, the differences between the two women became even more obvious than before. D had an affinity to be more free flowing, open to trying new things, had very flexible boundaries, and was indirect bordering on scattered. On the other hand, P had an affinity for bound flow, seemed to have some boundary issues thus causing her to be slightly skeptical when trying new things, and was mostly direct and structured. However, both of these women were able to express that the mid reach space was difficult for them. Near reach space was very easy and comforting for P, while far reach space was where D felt the most comfortable, although she sometimes lost her stability there. This can be highly attributed to the caretaking roles that both women assume. They were able to find the opposite poles of self and other; however, modulating between the two proved somewhat difficult for them. In fact, according to D, it is forgettable. I chose to stay within mid reach space a little longer than was originally planned. This was due to the confusion and
discomfort that I was feeling from the women and witnessing in their movement. I wanted to ever so slightly increase their windows of tolerance within this arena. This would possibly increase their awareness of the body felt sense of being able to care for someone else without losing the connection to themselves; thus, creating a pathway for learning coping skills.

Also, it is important to note that, this was the second week that P had complained of a physical problem. This could be a boundary that she had been implementing so as to not use her body for fear of bringing up something to make her “open her mouth.” In regards to the comment and movement about her daughter, that was the first time that P showed movement expression within her torso. Due to this, it can be hypothesized that there was a lot that P was holding inside of herself, which might have contributed to the physical problems that she constantly experienced.

**Session three.** For the third session, the yarn circle was again present, and calm music was playing. According to the goals of the treatment plan, for this session I planned on continuing with relaxation through movement, as well as, lifting and opening the body to combat the enclosing and downward nature of their depressive symptoms.

The session began with what had become routine dialogue and then a breathing warm-up. During this session I decided to bring a component of the intervention into the warm up. I chose to do breathing with a focus on the ideas of opening and closing. I applied this through verbal cues as I slowly guided the women through the warm up. I used gross and fine bodily actions in order to provide choices to which the women might relate. For example, I used opening and closing in reference to actual large scale movement, i.e. arms, legs, upper body, lower body, fingers, etc. Then I moved towards mid scale movement, i.e. chest, rib cage, lungs, muscles, etc. Finally, I guided the women with imagery through the movement on a cellular level. I moved on
to the next section of the group and added a tension and release tactic along with the opening and closing with imagery. I encouraged the women to utilize the imagery to “find their core” and tighten around it; in a sense “close around it.” Then I encouraged them to slowly loosen and spread in an opening fashion while still holding onto their core. I used imagery by describing a butterfly slowly emerging from a cocoon. As the women were moving through the experience, they began to physically move their bodies and open their arms, or their “wings.” When the women were almost completely expressing an open body, I noticed that there was a slight disconnect in the neck/head area. I encouraged them, with imagery, to spread their wings noticing the details and colors, and then notice their surroundings through “butterfly eyes.” With this, their heads began to lift and relax into the movement. I then guided them through figuratively flying around the room, looking down, and then returning to their safe place. The women slowly opened their eyes when they were ready and began to process.

This time, P had a lot to say. With a bright affect and lifted chest, she said, “It’s about really knowing your body--that’s all you have to think about…nothing else, just your body. It’s like a type of nirvana, actually.” D, also with a very bright affect and nodding head, said almost with a tone of surprise in her voice, “I was a butterfly.” I nodded and looked over to P, who playfully said, “You didn’t see me? I was flying around the room.” At this, I asked the women if they felt anything different moving this way. D said she realized that she felt free, but she could not figure out why and asked if I noticed anything about her movement. I took the opportunity to expose something I had found in her movement profile that she might be unaware of, and expressed that usually her upper arms were held tight to her torso, only allowing mobility from the elbows down. I expressed to her that once her upper arms were let go, it seemed like they had been “freed.” They were so light, floating, and open. I then probed her with a question,
“Hmm, I wonder what’s hiding under those wings?” To this D replied, “well, certainly something.” She then went on to express that when she was being a butterfly, whatever was under there would have to wait.

P then started talking about always being confident. With a very direct hand gesture she said, “I walk one foot in front of the other, keep a straight line…don’t waiver.” I reflected this statement back to P and she acknowledged what it could implicitly mean to her, as evidenced by a raised eyebrow and a “huh.” P had put much emphasis on this ideal, and since it was rooted in an expressed sagittal dimension, it prompted an exploration of the dimensions of space. I explained what each dimension signified in terms of space, how it applies to ourselves, our environment, our decision making, etc. P then asked if she feels the most comfortable within her vertical space while moving, why her inner self is so “out of whack.” She was referring to her digestive problems as she rubbed her torso with a circular motion. I used the opportunity to psychoeducate the women on the physical effects of stress and how the parasympathetic and sympathetic nervous systems cannot function effectively under stress.

Afterwards, I asked the women to pay attention to their affinities during the upcoming week and try at least one thing that we did during the session. Before we ended, D stated that she would definitely be trying some of the interventions (the breathing techniques, the imagery, etc.) at home due to the fact that the relaxation breathing that she had started practicing after the first session had been working. She expressed that she was empowering herself and making the time to “do the breathing” before she went to bed. She said she was seeing results not only in her sleeping patterns, but in her overall energy level and mood as well. P expressed happiness for D with a smile and “good for you.” The group ended with the breathing ritual while holding hands.
My observations of session three. There was a lot that happened in this group. First, P showed a side of her that had not previously been seen. She smiled, rose vertically, and seemed content for a few moments. The “butterfly” aspect really had a positive effect on her, to where she was even joking about it and being playful. It seemed as though she was slowly starting to warm up towards the group. Also, P was very inquisitive about her vertical self and was very interested in learning about herself more. At this point, P was beginning to explore her inner self, as opposed to only her external self. She was beginning to connect with her core and inquire as to the reasons that fueled her actions. Her sagittal nature was expressed during her statement about walking with one foot in front of the other. It almost sounded like a mantra, something that she must keep reminding herself. Or as if she had blinders on and she couldn’t see anything but one foot ahead on the straight path. This was a testament to her slight uneasy feeling within the group. She was so sagittal, that her horizontal way of connecting was lacking. It also makes sense when looking at her posture and movement affinities. She very rarely widened, spread, opened, and rarely even looked to the side. There is a possibility that the “butterfly” movement had such a positive impact on her because her body was craving the opening, lifting, expansive movement that the experiential allowed. This may also be a reason why she felt inclined to speak so much, inquire, and become actively engaged in the processing aspect of the group by asking questions, giving opinions, etc.

The fact that D was able to acknowledge that there was something “hiding under her wings” was very important. While she gave it a thought in simply making the acknowledgement, she also was able to separate herself from it. She was able to create a boundary and said that it would have to wait because she was attending to herself. This was a large accomplishment for D, especially because she presented difficulty with tasks associated
with attending to herself when she felt the need to help others.

Lastly, the fact that there were questions asked and answered during this group displays a sense of trust that had developed within the group between the clients and the clinician. At this time, the potential ageism treatment barrier did not seem to play a role within the interaction. The educational/informative aspect of this group addressed that concern. This was evidenced by the way that both women shifted their affect into a vertical, wide-eyed, almost surprised expression. Both women, P especially, were very interested in the information given in regards to the effects of stress on the nervous and digestive systems and welcomed it as helpful. They responded to the information positively and noted that they would both try and remember it in order to assimilate it into their daily routines for the further promotion of health and wellness. This can be seen as forward progress towards the goal of finding the balance between caring for self and other and the building of the therapeutic relationship in and of itself.

Session Four. The plan for the fourth session was to begin with a self assessment. The sessions were halfway over and I wanted to see if the women had noticed anything different. Also, due to the explanations of the space dimensions the previous session, I wanted to take the intervention further so that the women could experience the physical sensation. Therefore, I planned on moving through the defense scale during the fourth session. This would mean that the women would have to be standing for the first time, a definite change for them, especially because they had been closing their eyes during the movement sections of the previous groups. In order to experience the defense scale and keep their balance, their eyes would have to be at least slightly open. This would increase their risk taking, being seen by another, as well as possibly bring them into full bodied vertical grounding. I felt that because the women had been practicing self awareness, they were ready to find strength and support from their own bodies
and the floor as they stood without the support of the chair.

The session began as the others had, with the circle of yarn around the chairs, the soothing music playing upon entering the room, and the opening dialogue. When I acknowledged that it was the beginning of the fourth group, and we were halfway through the group sessions, I asked the women if they had noticed any changes during the past few weeks. D immediately acknowledged that she had been “doing her breathing” and she was sleeping because of it. Also, she was very proud to report that her constant headaches had subsided. D said that she felt “shocked,” but at the same time, “relieved.” She then vowed to continue with what she was doing. P, on the other hand, immediately led with her thoughts of pain and negativiy, her usual way of answering. She expressed that she was on anti-biotics that day due to sinus pain. However, she did say that she had been trying to slow down while eating because she remembered talking about the digestive system not working well under stress. She said that instead of going straight home and quickly eating something, she had been quietly relaxing on the couch first then slowly making her meal and eating it mindfully. She said it was helping a little, but it might be “too soon to tell.” P also said that she had found herself to be more aware of her surroundings. With this, her gaze shifted indirectly from side to side and she added that she was slowing down. She attributed it to being cautious. I asked P what she was being cautious of and she replied, “Falling.”

Due to the fact that the women were so receptive to imagery, I chose to use this technique as an aspect of the warm-up for this session. I utilized imagery to facilitate a movement warm-up focused on breathing, opening and closing, and the head tail connection. I wanted to warm up the verticality and strength within the spine so that there would be a smoother transition to standing. I again used the imagery of wings for opening and closing, yet this time added the
component of a connection to the back through the scapula. I encouraged the women to imagine/feel their scapulas as very large wings that moved with their breath. I slowly guided them through a movement towards the spine, using the image that it had become seaweed. This encouraged a free flowing aspect to the spine and helped them relax into that place before they had to empower it in order to engage their strength. I then slowly decreased my level of direction and encouraged the women to listen to their bodies, stating, “how does your body want to move? Follow the impulse to move.” Both women began to become more free in their movement and it seemed less manufactured. There was also more fluidity in their connectivities at that point, and they both breathed in conjunction with their movement. After the warm-up concluded, I acknowledged that I had been slowly giving less direction, and asked how they felt about being leaders in their own movement. D agreed with a bright affect and expressed that she loves learning about herself. P added that it felt “lovely.”

When it was time to do the defense scale, I presented it to the women and explained that it would be an extension of the discussion we had the week before. Before I had to say anything, D suggested that we try it standing up. P expressed that her body was sore, but that she would do the best she could. We moved through the entire sequence three times. The first time we focused on breath, the second, on shape flow support, and the third, on full bodied movement. D was able to complete the entire series while standing; but P sat down during the beginning of the second time through it. D seemed like she was intently focusing and concentrating, which was causing her to bind her flow. I decided to add a breath powered swing, first cycling sagittally from front to back then with a horizontal twist from side to side. P, although sitting, participated as much as she could. Both women seemed to relax and release some tension after the swinging. After it was over, and D and I sat down, I asked the women how they felt. D expressed that she
“felt strong” in her legs, “like a tree.” P jumped in and said, “I am very aware of my back…also, my legs.” I asked P, “what about your back are you now more aware of?” She replied, “It holds me up and sometimes gives me pain.” I acknowledged both the positive and negative aspects of her reply. However, I brought attention to the fact that she led with a positive aspect. She was very surprised at this as evidenced by her smile and vertically lifted eye brows. D then remarked, “I only notice my body when it hurts.” Here, P nodded her head in agreement, then with a laugh said, “Wow, I opened my brain today, who woulda (sic) thunk (sic) it.” D laughed and excitedly said, “I’m going to go home and do all of these!” After this exclamation, and the women expressing that they had nothing extra to share, the group ended with the holding hands breathing ritual.

My observations of session four. The emerging theme from the fourth group was that of awareness. This encompasses awareness of self, other, and environment. The women were very open to trying something different during this session. It seems that the level of trust within the therapeutic relationship was building.

I chose to give the women more freedom in their own movement during this session because I wanted to give them the opportunity to be leaders in their own process. I felt that because the past weeks were about getting to know themselves, exploration, and awareness, that now they could try another way of exploration through authentically moving. I also felt that the environment and cohesion of the group had fostered a sense of trust and non-judgment where it was safe to try something different, thus empowering them and building self esteem and confidence. With these aspects at the forefront, I felt that they were ready to take more control in their own processes. In regards to P, there was a switch in her movement, attitude, affect, etc. after the movement intervention. She was not complaining about pain at all, she even led with a
positive statement. This, in and of itself, was a huge change for P. It shows that she was able to let herself, if even subconsciously, have a positive viewpoint. Also, in conjunction with the playful nature and very positive affect with which she presented during the previous session, this was a step forward. It demonstrates the way she was progressing toward achieving her goals in regards to increasing her self esteem, self worth, and combating her symptoms of depression.

This session marked the first time that the women did not simply vent to each other. They were truly involved in their processes as individuals. There were no references to anyone else but themselves. This demonstrates the amount of self insight that the women had started to employ as well as a possible coming to terms with their situations. When the women became involved in their own processes, feelings, emotions, and opinions flowed without much hesitation. This also displayed the level of trust that had been reached within the therapeutic relationship.

Both women said that they were taking time in their schedules and routines to make time for themselves. This was an accomplishment and a positive change. They were proactively working on ways in which they could make their situations easier, whether by mind or body techniques. They were taking control. Every session, D came in talking of how shocked she was and how much “doing the breathing” was working for her. She was bright and excited. P, while not as excitable as D, was presenting a change in her attitude. She was smiling, laughing, making jokes, and had an overall pleasant demeanor. While she was still fighting a physical battle internally, she was showing signs of not passively succumbing to it. For example, she tried the warm-up and the defense scale, although she could have easily just sat and watched.

Session Five. During the day of the fifth session, I received a phone call from D stating that her husband was being taken to the hospital and that she would be unable to make it to the
group. Coincidentally, I was thinking of possibly cancelling the group due to a personal illness that I had. I made the decision to cancel the group and made sure to let P know that it was being cancelled as well. I made the necessary arrangements to get in contact with P as she would already be at the site visiting her husband and not available via telephone. I received confirmation that P was notified within a few hours. Both women were assured that the group’s last session would still occur the following week. This cancellation only serves as a testament to the situations that these women deal with daily. D had said that she “hate[d] to miss the group, but my first priority is him.” I acknowledged D’s feeling of being pulled in two different directions and encouraged her to make sure that she not only was there for her husband, but that she also took care of herself during that stressful time. She agreed that she would try and added that she would do everything she could to be present with the group for the last session.

**Session Six.** Even though the fifth session was cancelled, the sixth session was to be the last, due to the fact that the women had only planned on six weeks within their schedules. For this session, I had planned a focus on coping skills, as well as, the post test and closing discussion. However, due to the events of the week before, I had to be more flexible with my plan than usual. Also, the time frame was challenged, due to the fact that the group started slightly late because we were locked out of the Creative Arts Therapy Studio. I was able to utilize the Behavioral Health office where my supervisor and the social workers have their desks and borrow a CD player from the Activities Department. A sign was placed on the door to knock if someone had to come in and the door was shut. I quickly arranged the chairs in a circle and the women and I took our seats.

First, I acknowledged that this week was a little different (i.e. no yarn circle, no soothing music upon entering, a quick shuffling around the second floor for usable space, and a setting up
of the space while the women were in it). I acknowledged that like the events of last week, things change at the last minute and the ability to be flexible may have an impact on the outcome or one’s mindset during the situation. P seemed to be very flexible and amenable to the situational change; and although D was going along with us, she seemed unusually quick, tense, and stressed. After the ritualistic beginning dialogue, I wanted to check in with D and see how she and her husband were doing. She talked briefly about the status of her husband and that he was recovering well. She also mentioned that throughout the week, she received support from P, “even more than usual.” She thanked her and P nodded with a smile. I took this time to transition to the focus of the day, introducing coping skills and the fact that social support is a major way to cope with difficult and/or stressful situations.

The warm-up I planned was a relaxation with imagery. I decided to start from the head and work top-down this time because I felt the women were well practiced in “getting into their body” so they could mentally relax into the practice. I used the idea of water to facilitate the movement and healing properties of breath throughout the entire body. I used describing and cue words such as “cleansing, carrying, relieving, releasing” etc. in order to help guide the women in the process of letting go of tensions and stressors. When I arrived at the core, I used the word “cradle” to describe the action of the pelvis in regards to the flow of figurative water and the sensation of everything that it was washing “into a bowl” within the pelvis. This idea seemed to not only have an effect on the women internally, but physically as well. Both of their torsos shaped and their bodies seemed to form the cradle I had been describing. I encouraged them to acknowledge what was in the bowl, what stressors and tensions they were getting rid of. Also, I asked the women to make a mental note of what emotions came up as they explored the contents of the “bowl” that they were “cradling.” When they were ready, I encouraged them to let go of
those emotions if they wanted to, and to figuratively tip the bowl, letting the water flow downwards again. I guided them through moving the water/breath down their legs, through their ankles and feet, then back into the earth “where it came from.” I was planning on ending the relaxation at this point, but when I noticed that the women were still very much involved in what was happening, I decided to go with it. I continued onward by adding another component. I encouraged the women to experience the “going out” through their feet and the “coming in” through their nose. I encouraged them to use the imagery of a “vessel.” I guided them through imagery of the water being slowly replaced by breath, and letting the breath then take up the space where the water had washed tensions and stressors away. At this point, I related the flow of breath to a sagittally cycling circle: coming in through the top, going out through the bottom and then coming back in again. I reminded the women that there was no beginning or end. I feel that incorporating the idea of a continuous flow helped to foster the experience of modulating between the self and something external. I also feel that this idea helped to encourage an experience of continuing to hold to on the self while being attentive to other. I used the cue phrase, “modulation through self and environment” then transitioned to “modulation through self and other.” After letting the women experience this for a while, I guided them into slowly bringing their awareness to the room and their surroundings.

After sitting in silence for a moment, a smile presented on P’s face. I asked her about it and she said, “I feel like a wet noodle. The tension from my neck is gone. I’m ready for sleep.” D then started to process aloud. She said, “I noticed that I let go of my emotions when you gave the choice. Right then my stress started to really leave.” I returned, “So, you feel that your emotions are connected to your stress?” D agreed stating, “Absolutely! To relieve stress you have to deal with the emotions, I realize that now.” I acknowledged D’s change in attitude.
towards herself and her feelings and asked P if she has noticed a change in herself. She expressed that she has continuously noticed a change in her self-awareness and in attending to the needs of her body. She had been continuing her new practice of sitting and taking time before and after meals, and had added reading leisurely and watching television. I said, “I see you’ve been taking time for yourself, nourishing yourself. How has that been for you?” P expressed that “it feels nice. I’ve never really done it in this way before.” The topic of permission then came up. The women discussed a change in their views in regards to being able to give themselves permission to do things and not feel guilty about it later. D then remarked, “I’m dealing way better with things than I could before. Then, I was dealing because I had to, I had no choice. But now, my headaches are completely gone, and I’m sleeping more than I ever have. I’m more relaxed, I can feel it. I’m sitting with (husband’s name) in the hospital and able to still relax.” I asked her to explain. She said that she’d been practicing breathing while she was in the hospital with her husband. She was able to realize when she was getting anxious from her body cues. She said, “I didn’t want to let it all take me over.” I said, “So you can take care of you and your husband at the same time?” With a very bright affect, vertical rise, and widening shoulders, she said, “Yeah, I guess I can.” Here, P smiled and said, “No, you know you can.” To D, I acknowledged, “It sounds like you’ve found your middle ground; the ability to be there for someone else and take care of yourself at the same time.” Here D exclaimed, “I have! Yes!” accompanied by a head nod, a smile, and a quick full bodied vertical rise. When the women made clear that they had nothing more to share, I closed the group with a brief summary of the changes that the women had experienced, and what coping skills they had already been starting to employ in their everyday lives. I acknowledged the profound improvements in awareness and insight on the part of both women and also, as per IRB requirement, made sure to encourage
them to seek support from any other social work support groups within the site. D said that she might try to go to one of the groups and P offered to take her along. With this, I thanked the women for their time and asked for them to stay a few minutes to fill out the post-test questionnaire. We then held hands and completed the group with the closing breathing ritual.

*My observations of session six.* The session started with a change in routine. Both women seemed to handle the last minute changes very well, as evidenced by their calm affect and verbal statements. D was quicker in her verbalizations and movement than she had been normally when she came in, but was still relatively easy going in regards to the changes. When we finally sat down in a circle and began the warm-up, D was able to slow down her body at a very quick rate. It seemed as if she was able to drop into her body faster than ever. Since she had been utilizing this practice at home, it is possible that because it was becoming more familiar, it was easier to access. After the relaxation, D spoke slowly and softly. When it was pointed out to her, she noticed the change in herself. During this session, P remained positive the entire time and did not speak in a negative fashion. In regards to P, her movement was very different during the last session. Her flow was free, her chest was wide and open, and her breathing was even and quiet. These are completely the opposite of the way that P presented during the first few sessions. During session six, she was simply sitting, with seemingly no agenda. Before all of the groups, P’s movement/affect had an anticipatory quality, coupled with a vision pattern that could suggest evaluation, or trying to figure something out. During session six, it seemed that she was completely present and in a state of simply being. Throughout the last session, the women were more expressive than ever before. Each was open and truly insightful to her own process and sometimes to the process of the other as well.
Results of the RSS

Pre-test. After looking over the results from the RSS pre-test, it became clear that one participant presented with more depressive characteristics and the other, with more anxiety. Also, because both women felt that their outside lives were affected in many instances, coping skills needed to be explored within the course of the sessions. For Client P, the pre-test results yielded seven of the 15 answers in the frequently, quite a lot category and one check mark in the always, considerably category. The second most frequent responses (four) were in the sometimes, moderately category, and three were in rarely, a little. These answers weighed heavily on one side suggesting large amounts of stress associated with the CD spouse’s situation. Client D’s RSS pre-test answers were weighed considerably in the middle. This participant only answered 14 of the 15 questions, not realizing that she had missed one. Nine of those 14 answered questions were checked in the sometimes, moderately column. One check was placed in the frequently, quite a lot column, while three checks were placed in the rarely, a little column, and one in never, not at all. The highest ranked answers for each participant were Is your sleep interrupted? and Has your standard of living been reduced?

Post-test. The post-test results showed a significant difference in the amount of stress burden felt by the CD spouses. For one participant, her pre-test consisted of 7 of 15 answers checked in the frequently, quite a lot and one check in the always column; the post test results showed zero checks in either of the two columns. Her pre-test also consisted of zero check marks in the never, not at all column; the post-test results showed four checks in this column. While there were many slight deviations (one column difference), there was one profound change for this participant. Question 11 is has your standard of living been reduced? Her answer in the pre-test was always, considerably. In the post-test, this answer was decreased down to rarely, a little.
All other answers decreased with the exception of one: question 14 *Do you ever get angry or cross with___?* This answer increased by one column: *rarely, a little* to *sometimes, moderately.*

The other participant had changes in her answers; however, nine of her answers stayed the same. Three answers increased by one column from the pre-test to the post-test, and three decreased. The most significant change from the results of the pre- and post-tests from this participant can be illuminated through question 10 *is your sleep interrupted?* Her pre-test answer was *frequently, quite a lot* and by the post-test was *rarely, a little.* This is the greatest change, spanning two columns.

At the end of the post-test, the women asked if they could make comments anywhere. To this I replied that it was acceptable to simply write out comments on the back of the test. The comments read:

D: “I have really benefited [sic] by this study. It has been a great feeling to be able to sleep better and relax a little more.”

P: “Excellent form of relaxation. Able to get in tune with my body.”

Although the notes and observations of the researcher are valuable, the direct quotes, whether spoken or written, from the participants hold much weight. These comments exemplify the reactions of the women in their own words after concluding the study.
## RELATIVE STRESS SCALE (RSS)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never Not at All</th>
<th>Rarely A Little</th>
<th>Sometimes Moderately</th>
<th>Frequently Quite A Lot</th>
<th>Always Considerably</th>
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<tbody>
<tr>
<td>1. Do you feel you can no longer cope with the situation (your spouse residing in LTC)?</td>
<td>XX</td>
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<td>2. Do you feel that you need a break?</td>
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<td>3. Do you ever get depressed by the situation?</td>
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<td>4. Has your own health suffered at all?</td>
<td>XX</td>
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<tr>
<td>5. Do you worry about accidents happening to ___?</td>
<td>XX</td>
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<tr>
<td>6. Do you ever feel that there will be no end to the problem?</td>
<td>X</td>
<td>X</td>
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<tr>
<td>7. Do you find it difficult to go away on vacation?</td>
<td>X</td>
<td>X</td>
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<td>8. How much has your social life been affected?</td>
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<td>11. Has your standard of living been reduced?</td>
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<td>12. Do you ever feel embarrassed by ___?</td>
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<tr>
<td>13. Are you prevented from having visitors?</td>
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<td>X</td>
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<td>14. Do you ever get cross and angry with ___?</td>
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In the following chapter, a discussion of the results of the sessions described above will be conducted and the research question will be answered. Implications and questions for future research will be examined as well.
Chapter V: Discussion

CD spouses are a subpopulation of caregivers and have, until recently, been overlooked. As the population grows older, many with dementia related illnesses are making the transition into LTC, thus leaving behind a CD spouse. This CD spouse is not receiving the care that the LTC spouse is receiving in order to deal with the transition. This study came to fruition in order to answer questions dealing with this problem. How can dance/movement therapy be a supportive counseling tool for use with CD spouses of a LTC resident diagnosed with a dementia related illness? If there is much support being given to the LTC resident by the CD spouse, then who supports the supporter? Answers to these questions and others illuminated by the research itself were found through the completion of these study sessions.

Findings

The findings presented in this study only began to touch the surface of the ways in which dance/movement therapy can help aid in the treatment of this sub population. As described in chapter IV, there were many positive reactions towards the process. For example, both women became more aware of their bodies and how mental and emotional stress is manifested in the body. They were also able to correlate certain emotions with certain bodily functions. Client D was able to realize that her headaches and disturbed sleeping patterns were caused by stress. Once she was able to experience, learn, and implement breathing and relaxation techniques into her daily routine, she expressed that her physical symptoms subsided. Also, she was able to realize that her emotions must be dealt with instead of trying to bury them and “keep going.” She learned coping skills necessary in dealing with issues that arise and was able to experience a sense of universality/normality with the other group member through processing and discussion during the sessions. Her posture changed and her movement repertoire increased to encompass
lifting and opening movements, as well as exploration of slower, intentional movements in order to decrease anxiety and improve awareness of her inner self. Client P took a slightly longer time before she began to express change. However, according to the RSS post test results, P experienced a greater amount of change than D did. P became more verbally expressive and also incorporated laughter and humor into her verbal conversation and processing. By the end, she had begun to lead her comments with positive statements and exhibit a decrease in complaints about physical ailments. She had begun to implement her learning and experiencing into her daily routine, as well as, discuss openly with D instead of talk to her from her accustomed “peer leader” role. Both women exhibited a decrease in depressive symptomology, a decrease in levels and symptoms of anxiety, and an increase in the ability to care for someone else without losing or neglecting themselves. These results were found in notes and observations of the clinician, as well as, direct quotations from the women themselves.

**Correlations with Other Existing Research**

The research that was examined earlier in chapter II correlates with the results found with this study. The women, although not fulfilling the stereotypical caregiver role, regarded themselves as the primary caregiver for their husbands. Later, after the women had been examining their own processes and gaining insight into themselves, they began to describe themselves in the same ways in which the research describes supercaregivers. Also, although anger never really became an issue brought to the surface during the sessions, the research suggests that anger and resentment are common for spouses of those with a dementia related illness. This can be supported by the results of the RSS and the questions surrounding frustration with the LTC resident spouse. Perhaps the most impactful correlation is the idea of increased risk for anxiety and depression found within the literature. Both of the women exhibited
symptoms of each; and as the literature suggests, coping skills, especially including relaxation techniques, were proven to be most effective. This was proven true within the course of the study. The women learned to employ coping strategies and began to see the benefits and positive results. Also to be noted is the idea in much of the research that all cases are extremely different, and should be treated that way. This was true for this study as well. Both women had different issues that stemmed from the same situation, requiring personalized treatment. This also helps to support the notion that peer-support and social groups should not be the only means of serving this population. The resulting evidence from this study, coupled with the research to support it, makes a case in favor of supporting the supporter with accessible treatment to aid in serving the population of CD spouses.

Limitations

Although there can be many positive aspects of a study, there must be negative ones as well. There can be no prevention of unexpected occurrences when working with human subjects. The limitations present in this study were few, but were impactful and should be considered. First, this study was a clinical case study and therefore, cannot serve to make generalizations about the subpopulation of CD spouses solely based on the experience of two women. Although these women represented a wide range of stages of CD spousal caregiving, there was still only one at each end of the spectrum. Another limitation of this research was that it was a short time frame. It lasted only six weeks, and was not longitudinal. It only encompassed aspects of the situational impact the women were facing within a short time frame, not including admission nor the full experience of having a spouse in LTC. Although there was the experience of the hospital admission of D’s husband during week five, there are many other situations that arise that were not experienced during the six week period. Perhaps the most
impactful limitation was the aforementioned cancellation of week five due to the hospitalization of D’s husband. The women missed one full week of the study; however, this proved to not be as detrimental as it could have been if the hospitalization happened more towards the beginning of the sessions. When the women came back in week six, they had expressed that they had been practicing and implementing changes to their routines already. Perhaps, this unexpected occurrence prepared them for being able to try to create change in themselves without the direction of the group. It should be noted though, that the unexpected cancellation of the group is a testament to the way that the lives of CD spouses are require flexibility. At any moment, a major change must be made and/or accommodated. However, the hospitalization of D’s spouse may have caused a skew in her post-test answers. D expressed that “it never ends” and the hospitalization may have increased her feelings of there never being an end to the problem, as reflected in the change between her pre and post test answers. This adds to the findings of Allen (2006) in that a client said, “there is no off switch” (p. 57). There is no cure for Alzheimer’s disease or other dementia related illnesses as of yet; therefore, no amount of treatment can make the problem disappear. This study was implemented in order to alleviate some of the pressures that the CD spouses encounter by providing support and developing coping skills in order to deal with the situations in the healthiest ways possible.

Implications for the Field and Further Research

The results of this study will serve to illuminate the importance of DMT with this population, as well as the importance of including this population in the study of the elderly and those affected by dementia related illnesses. These results may also impact the field of DMT by increasing awareness of the subpopulation of community dwelling spouses in order to target another aspect of the population of dementia with DMT. It can help to offer positive research as
reasons to employ dance/movement therapists as part of a treatment team in LTC settings, thus furthering job opportunities for dance movement therapists. Due to the aging of the Baby Boomers, the Alzheimer’s Association reports that “By 2030, the segment of the US population aged 65 and older is expected to double. At that time, the estimated 71 million older Americans will make up approximately 20 percent of the total population” (Alzheimer’s Association, 2010, p. 12). With this statistic, there will obviously be the need for more services to help the CD spouses. The results of this study provide some evidence that DMT is a beneficial tool for working with a sub population that will only increase in size, importance, and relevance in the near future.

In addition to furthering the field of DMT, the long term effect may be the possible impact that this research could have on the support services found within LTC facilities from the point of admission throughout the full institutionalization of a resident. The project may increase awareness in regards to the treatment approach of the issues that arise specifically within this population. Secondly, LTC facilities can also benefit from the possible findings of this study. Results may help to instate better marketing due to the ability to extend/offer supportive services/therapy in the form of DMT and counseling beyond the central client focus to those closely connected to the residents. This is important due to the rapidly growing elderly population and the need for placement. This study, involving DMT as a supportive counseling tool, could help to bring such an occurrence into consistent facility routine, alleviating some pressure from case-loaded social workers to extend services to family members. In addition, it may help serve to bridge the gap between the community and the residential facility.

However, due to the limited amount of research on the topic, there are many larger questions that may arise that have gone beyond the scope of this study. They include, but are not
limited to: How can DMT be a supportive tool for counseling CD spouses when the spouse with dementia has recently passed away? How would DMT sessions with other CD spouses affect the relationship/treatment between the CD spouse and the LTC facility resident spouse? How would being part of a therapy group with other CD spouses and marriage/family therapy work together to offer more well-rounded support? These and other questions could be answered with future research and the utilization of the results of this study as a beginning point. Hopefully, more research will be conducted in order bring this topic to the foreground so that the sub population of the CD spouse does not go underserved much longer.

This thesis was intended to answer the question: How can DMT be a supportive counseling tool for use in the treatment of CD spouses of LTC residents who have been diagnosed with a dementia related illness? Through exploring the literature surrounding the topic and conducting a six week dance/movement therapy clinical case study group, several answers to this question have been discovered. Although the results of this clinical case study cannot be generalized to give a definitive answer to this question, it can provide evidence to support it. It is the hope of this clinician/researcher that this thesis will serve to raise awareness of the issues that CD spouses face and begin to bridge the gap within the research.
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Appendix A

Glossary of Terms

Community Dwelling (CD) Spouse

The spouse residing within the general community after the spouse with a dementia related illness has been admitted to a Long Term Care facility.

Dance/movement Therapy (DMT)

Dance/movement therapy is a counseling modality based on the idea that the mind and body are connected and can influence each other. A major goal of dance/movement therapy is to help an individual gain a sense of wholeness through the integration of the physical, emotional, and cognitive aspects of the self (Levy, 2005).

Dementia

Dementia is classified as a progressive and organic brain disorder for which there is no cure. There are many types of dementia, the most common being Alzheimer’s disease. It is marked by symptoms including loss of memory, aphasia, loss of executive functioning, behavior and mood disturbances, and a gradual loss of the sense of self (Erenberg, 2007).

Laban Movement Analysis (LMA)

Developed by Rudolf Laban, LMA is a way of analyzing movement through four basic categories of body, effort, shape, and space (BESS). It is also seen as a tool to aid in identifying the dynamics of a client’s movement in relationship to self, other, and environment (Bartenieff, 2002).

Long Term Care (LTC)

This term refers to a facility in which older adults who can no longer be cared for at home reside. These residents may or may not have dementia related illnesses. The site that was
utilized for this study group was a Skilled Nursing Facility where residents receive care at all times of the day. This particular LTC facility is separated by level of need and includes an Alzheimer’s Special Care Unit.
Appendix B

Recruitment Letter

Dance/movement therapy with spouses of a long term care resident diagnosed with a dementia related illness

Principal Investigator: Karla Karpowicz
MA candidate – Dance/Movement Therapy and Counseling

Dear prospective group study member,

With the recommendation of this Social Worker, you are invited to participate in a master’s thesis group research study comprised of 4-7 other spouses to answer the question: “How can D/MT be a supportive counseling tool in the treatment of an individual whose spouse, due to a dementia-related illness, resides in a Long Term Care facility?” You are being asked to participate because you not only fit the description of being a spouse of a long term care resident with a dementia related illness, but also, because deciding variables including, but not limited to, health, transportation, and ability to participate make it possible for you to be a candidate for participation.

You may be wondering what Dance/movement therapy is and what you will be asked to do. More details will be given in the informed consent; however, I can give you some brief information now. Dance/movement therapy according to the American Dance Therapy Association is “the psychotherapeutic use of movement as a process which furthers the emotional, physical, and cognitive integration of the individual.” Basically, what that means is that we can use aspects of dance and movement to help enhance the communication between the body and the mind. We can utilize this means of outward expression to understand our inner feelings and to deal with any stressors that we may have. It can help us deal with the effects that emotional stress can have on the body. Due to the group setting of this study, you may find that you are not alone in experiencing the stressors that come with having a spouse in LTC. You may also find some support from others in your same situation, or find that you can offer support to them. If you decide to participate you will always be asked to do what you can, take breaks if you need to, and understand that there is no “wrong movement;” everyone’s movement will look different because we are all different. It is always okay to be yourself. The movements that we will use will be mostly in the form of “everyday” movements and will accommodate all ability levels of the group members.
If you decide to participate, you will be asked to sign a form and it will be a record of your agreement to participate. This process is called ‘informed consent’ and will be administered by a witness, here at (site). You will also receive a copy of this form for your records.

If this sounds like something that you would be interested in, please contact me via the information below as soon as you decide so that we can get started. Space is limited and participants will be selected on a “first come first serve” basis.

Thank you for your time,

Karla Karpowicz –MA candidate Dance/Movement Therapy and Counseling through Columbia College Chicago, Chicago, IL

(XXX) XXX-XXXX

karla.karpowicz@xxx.xxxx.xxx
Appendix C

Recruitment Poster

Are you the spouse of a long term care resident who has been diagnosed with a dementia related illness?
If so, you may be eligible to participate in a 6 week group study.

This study will be focused on answering the question: Can Dance/Movement Therapy act as a supportive counseling tool in working with community dwelling spouses of long term care residents who have been diagnosed with a dementia related illness?

No dance/movement experience necessary to participate, all movement is tailored to the suit the ability of the participant.

Groups will be held at (site name)

Space is limited so please contact:
(name) – Dir. Alzheimer’s Special Care Unit
(XXX) XXX – XXXX
Karla Karpowicz – MA candidate Dance/Movement Therapy & Counseling
(XXX) XXX – XXXX
Appendix D

Informed Consent Form

Columbia

Informed Consent Form

Consent Form for Participation in a Research Study

Title of Research Project: Dance/movement therapy with spouses of a long term care resident diagnosed with a dementia related illness

Principal Investigator: Karla Karpowicz
Faculty Advisor: Laura Allen
Chair of Thesis Committee: Lenore Hervey

INTRODUCTION
You are invited to participate in a research study to answer the question: “How can D/MT be a supportive counseling tool in the treatment of an individual whose spouse, due to a dementia-related illness, resides in a Long Term Care facility?” This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and the benefits of participating in this study, as well as, any known risks, inconveniences or discomforts that you may have while participating. You are encouraged to take some time to think this over. You are also encouraged to ask questions now and at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. This process is called ‘informed consent.’ You will receive a copy of this form for your records.

You are being asked to participate because you not only fit the description of a spouse of a long term care resident with a dementia related illness, but also, because deciding variables including, but not limited to, health, transportation, and ability to participate make it possible for you to be a candidate for participation.

PURPOSE OF THE STUDY
After the transition to long term care (LTC), the community dwelling spouse no longer has the burden of physically caring for their spouse; however, there are many other stressors that these spouses still endure that should be addressed. The normalization and universality that a social support system, such as a therapy group, can provide may help to alleviate these stressors and help spouses to develop coping skills to deal with issues that may arise during the course of
institutionalization. The purpose of this research is to examine the ways in which Dance/movement therapy (D/MT) can be a supportive counseling tool to aid in the treatment of issues surrounding spousal separation experienced by community dwelling spouses of LTC residents diagnosed with a dementia-related illness.

**PROCEDURES**

- Upon approval of the IRB at both Columbia College and (site), consent form is signed by participants and dance/movement therapy sessions with a dance/movement therapy intern/MA-candidate will commence.
- Sessions will take place at (site) on a weekly basis, spanning 6 weeks, for 45 minutes at a time with a 1 pre and 1 post test utilizing the Relative Stress Scale (RSS) at week 1 and week 6.

If you agree to participate in this study, you will be asked to do the following:

- Be present for all 6 sessions
- Be truthful and honest in participation
- Participate to the extent of your ability in dance/movement therapy sessions that may include verbal/non verbal communication, movement interventions, and verbal processing. (movement interventions will be accommodated to meet the needs and abilities of group members)
- Keep the privacy of the other group members and happenings of the group confidential
- Release contact information to the principal investigator in order to make contact in regards to cancellations/emergencies that is to be confidentially disposed of after the group study has ended.

**POSSIBLE RISKS OR DISCOMFORTS**

The risks associated with participation in this study are minimal not exceeding the risk inherent in the regular scheduled programming and therapy groups at the (site) within the Creative Arts Therapy department or that concerning regular exercise and/or everyday movement. The movements that will be utilized during the course of the study will always be tailored to meet your needs. If at any time during physical movement, you feel tired or need a break, you are encouraged to do so. Possible inconveniences may include the time it takes to complete the study and challenging or difficult emotional issues that may arise. If at any time you feel that you may need extra assistance in dealing with the aforementioned issues, you can be referred to (site) staff (i.e. Creative Arts Therapists, Social Workers) for extra support during the course of the six week study. After the study has been completed, if you find you still need extra support, references for support groups
within (site) will be given. If you seek outside support once the study has been completed, some referrals can be provided to you; however, obtaining and paying for such services become your responsibility.

**POSSIBLE BENEFITS**
The possible benefits of being in this study include an advancement of knowledge of the field and experience of dance/movement therapy, counseling, and implications of dementia on relationship. It may bring a new awareness to the effects of dementia and living in the community while your spouse is in LTC. Other possible benefits include, but are not limited to, a possible new awareness of your relationship with your spouse, a possible new awareness of the effects of emotional stress on your body, developing coping skills and strategies that can help you in times of stress, a possible reciprocal validation of feelings through being a group member along with other spouses, and/or making connections with other people in a similar situation and learning that you can support each other through the process. It may also serve to be positively impact the support services at long term care facilities, such as (site).
I hope that your participation in the study may serve as a foundation for further research on this topic and help to bridge the gap in the current state of the research.

**CONFIDENTIALITY**
- All data that is collected, including but not limited to notes, observations, and quotes will be kept in a secure file within the Creative Arts Therapy department until the end of the study. Any electronic data in the computer system at the (site) will be password protected. Data will be destroyed upon full completion of the study.
- The study data will be released in the form of a presentation/publication of the findings culminating in a thesis project.
- Information will not be shared with (site) staff. The data that will be shared with others will be stripped of identifiable information to protect your identity.

**RIGHTS**
Being a research participant in this study is voluntary. You may choose to withdraw from the study at any time without penalty. You may also refuse to participate at any time without penalty. If you have any questions about the study or your rights as a research participant, you may contact the researcher or the faculty advisor listed above.

*Who do I contact if I have questions about the study?*
Karla Karpowicz-researcher  Laura Allen-Faculty Advisor
(XXX) XXX-XXXX    (XXX) XXX-XXXX

(name)-Assistant Director of (site)
(XXX) XXX-XXXX

Take as long as you like before you make a decision. We will be happy to answer any question(s) you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator (Karla Karpowicz (XXX) XXX-XXXX) or the faculty advisor (Laura Allen (XXX) XXX-XXXX). If you have any questions concerning your rights as a research subject, you may contact the Columbia College Chicago Institutional Review Board staff (IRB) at XXX-XXX-XXXX.

PARTICIPANT STATEMENT
This study has been explained to me. I volunteer to take part in this research. I have had opportunity to ask questions. If I have questions later about the research or my rights as a research participant, I can ask one of the contacts listed above. I understand that I may withdraw from the study or refuse to participate at any time without penalty. I will receive a copy of this consent form.

____________________________
Participant Signature:

____________________________
Print Name: Date:

____________________________
Researcher Signature:

____________________________
Print Name: Date:
Appendix E

Sample Relative Stress Scale

### Relative Stress Scale (RSS)

<table>
<thead>
<tr>
<th></th>
<th>Never Not at All</th>
<th>Rarely A Little</th>
<th>Sometimes Moderately</th>
<th>Frequently Quite A Lot</th>
<th>Always Considerably</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Do you feel you can no longer cope with the situation (your spouse residing in LTC)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Do you feel that you need a break?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Do you ever get depressed by the situation?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Has your own health suffered at all?</td>
<td></td>
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</tr>
<tr>
<td>5.</td>
<td>Do you worry about accidents happening to ___?</td>
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<tr>
<td>6.</td>
<td>Do you ever feel that there will be no end to the problem?</td>
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<tr>
<td>7.</td>
<td>Do you find it difficult to go away on vacation?</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>8.</td>
<td>How much has your social life been affected?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>How much has the household routine been upset?</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>10.</td>
<td>Is your sleep interrupted?</td>
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<td></td>
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</tr>
<tr>
<td>11.</td>
<td>Has your standard of living been reduced?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Do you ever feel embarrassed by___?</td>
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</tr>
<tr>
<td>13.</td>
<td>Are you prevented from having visitors?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Do you ever get cross and angry with___?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Do you ever feel frustrated at times with___?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>