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*Advance Illness Care Teams for Residents  
with Advanced Dementia*

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**Project Title**

Advanced Illness Care Teams for Nursing Home Residents with  
Advanced Dementia

**Lead Nursing Home**

Ozanam Hall of Queens Nursing Home  
42-41 201<sup>st</sup> Street  
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**Affiliated and Other Participating Nursing Home**

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## **Section I: Goals, Objectives, and Hypotheses**

### Goals

The primary goals of this project were to improve end-of-life care and pain management for nursing home residents with advanced dementia at two New York City nursing homes. It was also hoped that there would be a change in culture at both facilities to support and reinforce these improvements to end-of-life care and pain management for residents with advanced dementia. In working toward these goals, each resident's family or identified surrogate was invited to participate in several meetings to learn more about this project and to offer their perspective on the care given to their loved one.

In striving to achieve these goals, Advanced Illness Care Teams (AICT) were established at both nursing homes. AICTs are interdisciplinary teams that encourage the participation of medical, nursing, pastoral, recreation, rehabilitation, and social work staff in the development of individualized care plans for residents with advanced dementia. The concerns of family members also shape and inform the care planning process through ongoing communication with nursing home staff and opportunities to participate in the AICT meetings.

### Objectives

The AICT model of care was instrumental in working towards these overarching goals. Given the important role played by the AICT in this project, several objectives were specified to evaluate the effectiveness of the AICT, ensure its survival, and to make this model of care available to other facilities. These four objectives are listed below.

1. Evaluate the effectiveness of AICT for improving the quality of life, adjustment, comfort, and participation in health care decisions of surrogates and nursing home residents with dementia.
2. Evaluate the effectiveness of AICT for improving family members' satisfaction with the care of residents with dementia.
3. Ensure that the AICT program continues in the two participating nursing homes after the study ends.
4. Prepare an AICT implementation manual for dissemination to other nursing homes in New York State.

In operationalizing these objectives, residents from Ozanam Hall (Queens) and from St. Patrick's Home (Bronx) were recruited to participate in this study. Residents who met the screening criteria for participation in this study were randomly assigned to AICT or UC (usual care wait-list control) conditions.

### Hypothesis

The hypothesis for this study was that nursing home residents assigned to the AICT would experience significant ( $p < .05$ ) decreases in pain, discomfort, depression, and agitation compared to residents assigned to the UC condition.

## **Section II: Background and Rationale**

There have been numerous calls in the literature, by scholars and clinical nursing home staff, for research into better end-of-life (EOL) care programs and practices for persons with advanced dementia (Mitchell et al, 2004; Volicer & Hurley, 1998; Volicer & Bloom-Charette, 1999). However, there have been few attempts to evaluate intervention methods to improve EOL care for nursing home residents with dementia. The importance of this issue for residents and their families demands that we learn more about EOL care in spite of the difficulty in carrying out research with this population.

The difficulties in conducting this kind of study include applying rigorous research designs in the nursing home context and establishing measurement approaches for residents who are non-verbal or who can't self-report reliably. There are also important ethical and regulatory considerations which staff and families tend to avoid until a medical crisis occurs. Although these can be significant challenges, this project utilized methods that addressed these challenges in a rigorous, humane, and scientifically sound manner.

In view of the challenges associated with carrying out research in the nursing home setting, why use this setting? This setting was chosen because, increasingly, nursing homes are the site of terminal care for older adults. Nursing homes have an annual mortality rate of over 25%, and this rate has been rising over the last 20 years (Hanson, Henderson, & Rodgman, 1999; Holzman & Lurie, 1996; National Center for Health Statistics, 1996; Zerzan, Stearns, & Hanson, 2000). More than 500,000 people die annually in nursing homes, representing about 20% of the total mortality in the United States (Federal Interagency Forum on Aging Related Statistics, 2000; Zerzan, et al., 2000). Given this mortality rate, it is projected that over 20,000 of the almost 120,000 people in nursing homes in New York State are likely to die each year (AARP, 2000).

In respect to individuals living in nursing homes, it has been estimated that 50% to 70% have dementia (Rovner & Katz, 1993), and this prevalence rate is not likely to decrease in the near future. This prevalence rate is not likely to decrease because dementia increases exponentially with increasing age (Khachaturian & Radebaugh, 1996) and, in the United States, longevity is on the rise. With this aging of the American population, particularly the explosion in growth of the oldest-old (those over 85), it is expected that more and more nursing home residents will have dementia. This anticipated increase points to the growing need for EOL care, including palliative care measures, for nursing home residents who are terminally ill.

While there is a growing need for EOL care in nursing homes, hospice care is not being used to meet this need (Casarett et al, 2005). Although the use of hospice, in general, is on the rise, the growth is attributable to patients accessing this service from settings other than nursing homes. According to data from 1997, only 1% of nursing home residents were enrolled in hospice care programs which is about 13% of all hospice patients (Zerzan et al., 2000). Even though dementia is a terminal illness, most hospice programs do not provide services to individuals with dementia even if they are in an acute care setting. In fact, only

21% of hospice programs served dementia patients in any setting i.e., community, hospital, or institutional (Hanrahan & Luchins, 1995).

There are several reasons for this low level of utilization. First, health care policies discourage the use of hospice care among nursing home residents with dementia because it is often difficult for nursing homes to certify that these residents are in the last six months of their lives. Dementia has a lengthy deteriorating course and even the end stage may last two or three years (Schuster, 2000). Second, reimbursement schedules favor restorative care and technologically sophisticated procedures which are more intensive and specific in focus than palliative approaches. Finally, there are also concerns about charges of health care fraud resulting from the inappropriate certification of individuals for hospice services.

Despite the lack of hospice care in nursing homes, there is some evidence from studies in other settings that hospice and palliative care could enhance nursing home services because these approaches are more effective than the usual care received by terminally ill patients (Hearn & Higginson, 1998; Miller, Gozalo, & Mor, 2000). A more recent illustration of this can be seen in a study of New York State nursing homes. This study found that residents with advanced dementia are not treated as terminally ill patients and, therefore, are more likely to suffer through aggressive medical interventions than residents who have cancer (Mitchell, Kiely, & Hamel, 2004). These interventions often result in inappropriate transfers to hospitals and “may be associated with poor quality of care” in the nursing facility (Saliba, et al., 2000, p.154; Ouslander, Weinberg, & Phillips, 2000).

Further compounding this issue of inappropriate transfers from nursing facilities to hospitals are the potential problems with aggressive interventions in patients moving through the last stages of a dementing illness. Several studies have shown that in residents with advanced dementia, interventions such as artificial nutrition and hydration may not extend life but, rather, may cause painful side effects (Gessert, Mosier, Brown, & Frey, 2000; Huang & Ahronheim, 2000; McCann, Hall, & Groth-Juncker, 1994; Mitchell, Kiely, & Lipsitz, 1997). The AICT, like hospice and other palliative care approaches, offers an alternative to EOL care that closely monitors pain and encourages the establishment of advance directives as a way to give the patient more control of the dying process.

The issue of patient control is central to alternative care approaches but is often absent from traditional care. A study examining the implementation of the Patient Self-Determination Act (PSDA) in New York City nursing homes found that only 37% of the homes had written procedures to determine a resident’s decision-making capacity about advance directives (Mezey, Mitty, Rappaport, & Ramsey, 1997). A more recent study found that documented discussions of advance directives had only increased from 20.3% to 36.7%, and that discussions were narrowly focused, suggesting that residents’ and family members’ roles in medical-decision making were limited (Bradley, Peiris, & Wetle, 1998). In a qualitative evaluation of the impact of PSDA, Walker and colleagues also concluded “problems concerning the roles of institution, families, and staff in promoting resident autonomy persist” (Walker, Bradley, Bechner, & Wetle, 1998, p.83).

The AICT respects the autonomy of the resident and encourages the involvement of family members whenever appropriate. This is another feature that AICTs share with hospice and other palliative approaches that emphasize family involvement. The needs of both patient

and family guide care planning and treatment decisions. This is important because studies have found that families would like doctors, nurses, and social workers to offer social support and information on medical and follow-up care if they choose to forgo treatment for their spouses suffering with advanced Alzheimer's disease (Mezey, Kluger, Maislin, & Mittelman, 1996; Ward-Smith & Forred, 2005).

Families continue to need information and support as their terminally ill member passes from life to death. Just as families need guidance and support in making decisions to forgo life-sustaining interventions, they need assistance in grieving. But this need, too, is often neglected. For example, one study found that out of 121 nursing facilities surveyed, 99% did not provide materials or any services for family members and primary caregivers on the grieving process or bereavement after the death of a loved one (Murphy, Hanrahan, & Luchens, 1997).

The AICT model of care has the potential to fill these unmet needs. This model of care emphasizes the value of information, support, patient autonomy and family involvement in offering nursing home residents with advanced dementia and their families a bigger role in shaping end-of-life care. The quality of this end-of-life care and of the dying experience hinges on the ability to honor final wishes and to manage any pain or discomfort experienced by the dying family member (Patrick et al, 2003). The AICT, along with other palliative care approaches, promote the empowerment of the terminally ill individual and his or her family as they negotiate the stages of dying. And from a practical, economic perspective, the AICT provides a way to address the needs of nursing home residents and their families without hiring additional staff and without encountering the reimbursement and regulatory barriers associated with hospice care.

### **Section III: Methods**

*Study Design* – This study used a 2 x 2 x 3 randomized partial crossover design. There were two intervention conditions, two nursing homes, and assessments were done at three points in time. Nursing home residents were screened for eligibility and then randomly assigned to *treatment* (AICT) or *usual care* (UC) conditions. Treatment group residents were assigned to the AICT for a period of eight weeks. During this same period of time, the residents assigned to UC received ongoing care typical of the unit where they lived.

After eight weeks, the UC residents 'crossed over' to the AICT treatment condition along with residents randomly assigned to the treatment condition from the next cohort of residents. As before, the duration of treatment was eight weeks. At the end of the eight week period, the treatment group returned to the usual care condition as the residents assigned to usual care 'crossed over' into treatment along with residents assigned to treatment from the next cohort of residents.

The process of randomly assigning residents to treatment or usual care conditions repeated every eight to nine weeks over the course of one year. This resulted in six discrete intervention periods for each unit participating in the AICT project. A total of 120 residents were selected to participate in this study.

*Sample* – The sample of 120 residents was drawn from two units at Ozanam Hall and three units at St. Patrick’s Home. Both homes are skilled nursing facilities operated by the Carmelite Sisters for the Aged and Infirm. Ozanam is a 432 bed facility located in Queens and St. Patrick’s is a 264 bed facility in the Bronx. The sample size was determined primarily through a power analysis using NQUERY 3 software which specified 60 residents in each condition (AICT & UC) to have sufficient power (.8) to detect small to moderate effect sizes in the primary outcome measures.

All prospective participants were screened using three standardized instruments – 1) the Mini Mental State Examination (MMSE: Folstein et al, 1975), 2) the Global Deterioration Scale (GDS: Reisberg et al, 1982), and 3) the Activities of Daily Living Scale (ADL: Luchins et al, 1998). To qualify for inclusion in the sample, residents scored  $\leq 23$  (presence of cognitive impairment) on the MMSE and  $\geq 4$  (moderate cognitive decline) on the GDS. Both of these measures established a threshold of cognitive impairment for inclusion in the sample. In respect to physical disability, all participants needed assistance on at least four ADLs to qualify for the study.

Residents with serious medical complications (e.g. aspiration pneumonia, difficulty swallowing, and dehydration decubitus ulcers) were excluded from the study because their condition would require immediate treatment. This immediate need for treatment would preclude the random assignment to the AICT or usual care conditions and confound any effects attributable to the AICT. All residents selected for the AICT carried a diagnosis of dementia and many of the participants were diagnosed with Alzheimer’s disease.

*Data Collection* – Demographic and other data were collected on residents and family members/surrogates at baseline. This data included age, gender, education, income, marital status, race/ethnicity, and religious affiliation. Data pertaining to each resident’s primary diagnosis and co-morbid health conditions was also collected.

Data on the primary outcome variables was collected within two weeks of random assignment to AICT or UC conditions. Standardized instruments were used to assess *pain* (FLACC Scale: Merkel et al, 1997 & Pain Assessment in Advanced Dementia Scale: Warden, 2003), *agitation* (Cohen-Mansfield Agitation Inventory: Cohen-Mansfield, 1989), *depression* (Cornell Scale for Depression in Dementia: Alexopoulos et al, 1988), and *spiritual life* (spiritual assessment developed by nursing home staff). These measures were repeated at eight and sixteen weeks after the baseline assessment. Nursing, social work, and spiritual care staff all had data collection responsibilities on the outcome variables.

Each resident’s family member/surrogate was given a family satisfaction survey at baseline and at post-test. This survey was comprised of two instruments – the FAMCARE Scale and the Family Perceptions of Care tool. The FAMCARE Scale is a 20-item survey that measures the level of family satisfaction on a 5-point scale that ranges from very dissatisfied to very satisfied. The Family Perceptions instrument has 51 items which are each scored on a 7-point scale ranging from strongly disagree to strongly agree.

*Quantitative/Qualitative Methods* – A mix of quantitative and qualitative methods were utilized throughout this study. Quantitative methods were used in testing the central

hypothesis and in evaluating the variables of interest i.e. pain, agitation, and depression. In carrying out this analysis, a random effects regression model (RERM) was the quantitative method of choice because of its ability to include cases with missing data. Quantitative methods were also used in evaluating responses to the family satisfaction surveys that were part of this study.

Qualitative approaches were used in assessing the spiritual life of each resident, developing individualized care plans, and in evaluating family member comments on the satisfaction surveys. Although the spiritual assessment was developed 'in house' by nursing home staff for the two facilities in this study, there have been numerous instruments developed for taking a spiritual history or assessment in a variety of settings (see, for example, Puchalski & Romer, 2000).

*Data Analysis* - The equivalence of the AICT and UC groups were evaluated using Student's t and chi-square tests. In preparing for the analysis of the outcome data, non-normally distributed variables were transformed using square root transformations. The effects of Condition, Time, and Condition x Time interaction effects were analyzed using random effects regression models (RERM). The Condition x Time interactions were of particular interest since these reflect significant differences between outcome variables in the AICT and UC conditions over the course of the intervention period.

*Conclusions* – The design of this research study and the setting in which it was conducted ensured that a relatively homogeneous population would be selected for this study. The subject selection process included clinical screening, as well as the utilization of standardized instruments, to identify a pool of residents with roughly equivalent cognitive and functional capacities. Random assignment to AICT or UC conditions further increase the likelihood that any conclusions drawn from the results of this study will be attributable to the intervention being tested.

#### **Section IV: Results**

Table 1 summarizes the demographic data for all of the nursing home residents who participated in this study. The similarity of residents in the AICT and UC groups is evident when reviewing the data on education, income, gender, and race. There was a difference in the mean ages, however, with AICT residents averaging 84.82 and UC residents averaging 88.00. The large majority of residents had health care proxies and, in most cases, family members were identified as the resident's proxy.

The 3.18 year age difference between AICT and UC shown in Table 1 was significant at the  $p < .05$  level. Because of this significant difference in age, all outcome analyses were conducted with age as a factor. None of these analyses found interaction effects, therefore, age was not included as a factor in subsequent analyses. All analyses reported in the following section are for the main effects of Condition, Time, and Condition x Time interactions. The Condition x Time interactions are of particular interest since these show any significant differences between the AICT and UC conditions over a given period of time.



Table 2 shows the demographic data for the residents' family members who agreed to participate in the family satisfaction portion of this study. There are strong similarities among respondents in AICT and UC with most being married, white, and female. The average educational levels for respondents in the two conditions are also very closely matched at 15.41 (AICT) and 15.80 (UC) years. With respect to age, the 0.17 year difference between AICT and UC family members was not significant.

Table 3 shows the results of the RERM analysis. Included in this table is a summary of the AICT and UC resident scores on the variables of interest during the baseline to 8-week intervention period. The FLACC Pain Scale scores show a significant reduction in pain for residents in both AICT and UC conditions over the intervention period. This is a positive outcome that is expressed in Table 3 as a significant effect of time. On a less positive note, there is no discernible difference between AICT and UC groups in respect to a reduction in pain. Had there been a significant difference between the AICT and UC groups, a Condition x Time interaction effect would have been observed.

The most positive outcome in Table 3 is on the Cohen-Mansfield Agitation Inventory (CMAI). The CMAI is comprised of three behavioral subscales (aggressive, physically nonaggressive, and verbally agitated) which are shown in the table. The positive outcome is a significant Condition x Time interaction effect in the 'physically nonaggressive' (pacing, repetitious sentences or questions, inappropriate robing/disrobing, general restlessness, trying to get to a different place, repetitious mannerisms) subscale of the CMAI. This Condition x Time interaction reveals that AICT residents experienced a significantly greater decrease in physically nonaggressive behaviors than UC residents. This was the only outcome measure to reach statistical significance in support of AICT's superiority over UC in reducing targeted behaviors.

Although the results displayed in Table 3 offer only limited support for the superiority of AICT over UC, the data suggests that the residents in this study benefited from the AICT interventions. For example, the 'aggressive' and 'verbally agitated' subscales of the CMAI show significant reductions in the measured behaviors for residents in both conditions (AICT and UC) from baseline to the 8-week end point. Reductions in the mean scores were greater in the AICT groups than in the UC groups but this difference was not statistically significant. Also, there was a significant time effect for all three subscales as all variants of agitated behavior decreased over the 8-week intervention period.

The third outcome measure summarized in Table 3 is the Cornell Scale for Depression (CSD). The CSD has five subscales (mood-related signs, behavioral disturbances, physical signs, cyclic functions, and ideational disturbances) which are totaled to arrive at a 'total depression score'. Over the course of the intervention, AICT and UC groups reduced their total depression scores. However, the reduction in the total depression scores failed to reach statistical significance. The behavioral disturbances subscale was the only CSD subscale to register a time effect with a decrease in the mean scores for residents in both AICT and UC arms of the study. No interaction effects were observed in any of the subscales or in the total depression score of the CSD.

The last scale shown in Table 3 is the Pain Assessment in Advanced Dementia Scale (PANAD). There is a time effect noted in the table that is attributable to the drop in pain

scores for both AICT and UC residents during the intervention period. The AICT group experienced a larger drop in their pain scores than the UC group but the difference in the mean scores of the two groups was not statistically significant.

Three additional analyses were performed to discern any other possible treatment effects. Recall that in the crossover research design, the UC residents received the AICT intervention after participating in the eight week control condition. Therefore, a paired samples T test of the UC group was used to examine the two change scores: the difference between the baseline and post-test scores, and the difference between the post-test and follow-up scores. This test was performed to see if the UC residents showed any improvement after completing the AICT intervention. Although a decrease in the mean scores was observed on most of the outcome measures following the intervention, none of these reached statistical significance. This result may have occurred because significant time effects were already shown for control group participants from pre to post-test.

A second analysis (RERM) compared the effects of treatment for the AICT group from baseline to post-test, and the UC group from post-test to follow-up. This analysis helped determine if the intervention was effective for both AICT and UC groups. If the AICT intervention was effective for both groups, the analysis should reveal significant time effects but no Condition x Time interaction. After running the analysis, it was found that both groups experienced a decrease in the mean scores on most of the outcome measures. Significant time effects were observed on the FLACC and PANAD scales as well as on all three subscales (aggressive, physically nonaggressive, verbally agitated) of the CMAI. This indicates that AICT was effective in reducing pain and behavioral disturbances over time.

The third analysis that was carried out calculated effect sizes for each of the outcome variable analyses. A moderate treatment effect was found on the physically nonaggressive (.53) subscale of the CMAI. This is not too surprising since the physically nonaggressive subscale of the CMAI was the only outcome measure to achieve a significant Condition x Time interaction. In addition to this finding, a low-moderate treatment effect was observed on the verbally agitated (.33) subscale of the CMAI and on the mood-related (.33) subscale of the CSD. Although neither of these measures achieved a significant Condition x Time interaction in the first RERM analysis, the AICT mean scores decreased more than the UC mean scores on both of these subscales. This shows that the AICT group had a greater reduction in the targeted symptoms than the UC group but the difference between the two groups did not reach statistical significance.

Table 4 summarizes the results of the 'Family Satisfaction Surveys' administered during the course of this project. These surveys included the FAMCARE Scale and Family Perceptions of Care Tool. As shown in Table 4, the mean scores for AICT are higher than UC on both scales at Time 1 and at Time 2. This reflects a slightly higher level of satisfaction and more favorable perception of care in the AICT group although the difference is not statistically significant. In fact, both AICT and UC families were satisfied with the care their family member was receiving. This is reflected by FAMCARE scores in the 80 – 100 range which correspond to a satisfied – very satisfied level of satisfaction. The Family Perceptions scores also speak to the favorable view of care by resident's family

members. This is evident in mean scores in the 255 – 357 range which covers the favorable perceptions side of the rating scale.

Given the generally high level of satisfaction with care at baseline, and the stability of the scores between conditions and over time, it is likely that a ‘ceiling effect’ was operating in respect to the family satisfaction surveys. This is further supported by comments written on the surveys by family members at both pretest and posttest. These comments were consistently positive and reflected a high level of satisfaction with the care their family members were receiving.

## **Section V: Strengths & Limitations**

There are certainly many challenges in carrying out end-of-life research within the context of a nursing facility. There are measurement issues for nursing home residents who are non-verbal or who are unable to self-report reliably. Other pertinent issues include ethical considerations and regulatory guidelines that affect how this kind of research is carried out. In managing all of these contingencies, the overarching goal is to design a rigorous, scientifically sound research project that respects and supports residents and their families as they deal with end-of-life care issues. Striking a balance between the demands of sound research and the needs of families and their disabled members created a project with a mix of strengths and limitations.

One of the strengths of this study was that it utilized a rigorous, empirically grounded research design to determine the effects of treatment. A partial crossover research design was used and participants were randomly assigned to control (UC) or treatment (AICT) conditions. Random assignment is an important element of scientific research because it prevents selection bias in assigning participants to control and treatment conditions. The partial crossover design contributed to the strength of this study in that it allowed the control group to benefit from treatment by ‘crossing over’ into the AICT condition after serving as controls for an eight week period. The advantage of this design is that a control group is established but none of the participants serving as controls are denied the potential benefit of the treatment condition.

A second strength of this study, but also a limitation, was the homogeneity of the resident population. In reviewing the demographic data presented in Table 1 and in the preceding ‘Results’ section, it is clear that the nursing home residents in this study were very similar. Over 90% of the residents were female, more than 85% were white, and 70% were widowed. Their levels of cognitive functioning were also similar as indicated by the narrow range of scores on the Mini Mental State and Global Deterioration Scale. The advantage in having a homogeneous subject pool is that variability between treatment and control groups is minimized. Also, conclusions drawn by the study are more credible when applied to groups or populations that match the subject pool. The limitation of having a homogenous subject pool is that treatment effects are not generalizable to individuals outside the study population. In this study, for example, men and minorities were not well-represented.

Another limitation of this study was the failure to achieve statistically significant Condition x Time interaction effects on all but one of the outcome variables. Significant interaction effects would have pointed to clear differences between UC and AICT conditions over a discrete period of time. These differences, ideally, would confirm the hypothesis that AICT is more effective than UC in reducing symptoms such as agitation, depression, discomfort, and pain, which were targeted in this study.

In spite of this failure to achieve significant Condition x Time interaction effects, there were Time effects that showed a decrease in the mean scores on the FLACC, CMAI, PANAD, and on the behavioral disturbance (agitation, restlessness, slowed speech, reaction, and/or movements, multiple physical complaints, and less involvement in normal activities) subscale of the CSD. This decrease in the mean scores suggests that the residents in both UC and AICT groups experienced some improvement in their agitation, pain, and the listed behavioral disturbances over a given eight week period. Although these results do not demonstrate the superiority of AICT over UC in reducing the symptoms targeted in this study, the decreasing scores on the outcome measures are a positive finding that should not be overlooked or dismissed. Additionally, the significant time effects when comparing baseline to post-test changes in AICT participants with post-test to follow-up scores of the treated UC participants suggests that AICT may be effective in reducing pain and all three types of agitation that were measured by the CMAI.

This improvement in both groups could be attributable to a contamination effect from the AICT to the UC condition. This contamination may have occurred in the process of balancing the demands of research with the needs of residents and their families. More specifically, residents and their families began to engage in a helping partnership with researchers and nursing home staff prior to being randomly assigned to AICT or UC. For example, all families were invited to family informational meetings with researchers and nursing home staff. The purposes and goals of the project were described, questions were answered, and consents to participate in the AICT research project were obtained. This opportunity for families and staff to interact often resulted in the identification of problems followed by problem solving activities prior to the start of the intervention. Although this early engagement in team problem solving was consonant with the research plan for residents immediately entering the AICT condition, the residents assigned to the UC condition received a premature AICT benefit. This was a limitation born of the need to be responsive to residents and their families. In many instances, it would have been inappropriate to delay a response to these problems.

Additional opportunities for contamination of the UC group occurred because it was not possible to blind researchers, nursing home staff, and families to the AICT and UC conditions. This limitation was a consequence of the project's goal to engage all parties in the team process during the intervention period. During this eight week period, researchers, staff, and families collaborated to develop care plans that accurately reflected family concerns. There were several formal (team meetings) and informal (telephone calls, nursing home visits) opportunities for family members to participate in this process. The collaborative nature of the AICT intervention effectively precluded the blinding of key participants.

The Family Satisfaction Surveys that were conducted concurrently with this study provided valuable feedback about the perceptions and level of satisfaction experienced by the family members of the nursing home residents who participated in this study. The scores on the FAMCARE Scale and Family Perceptions instrument consistently reflected a high level of satisfaction with the care at both nursing homes. Written comments on the surveys repeatedly spoke of “excellent care” provided by “dedicated, caring professionals”. Many family members wrote that Ozanam/St. Patrick’s was the best possible place for their ‘loved one’ to be given the level of care required.

One limitation of these surveys was the ceiling effect described in the ‘Results’ section. This effect virtually eliminated the possibility of finding an increase in the satisfaction of families after the AICT intervention. Another limitation was the low percentage of complete survey sets which were comprised of surveys at baseline and post-test. There were just 58 of 118 survey sets that were completed (49%). These were mailed surveys and a higher rate of completion could undoubtedly be achieved through personal or telephone interviews.

## **Section VI: Conclusions**

The hypothesis for this study was that nursing home residents assigned to AICT would experience significant ( $p < .05$ ) decreases in pain, discomfort, depression, and agitation compared to residents assigned to UC. A significant difference between AICT and UC was observed on the physically non-aggressive subscale of the CMAI but this level of significance was not achieved on the other outcome measures. These findings provide only partial support for the hypothesis that AICT would be superior to UC in the reduction of pain, discomfort, depression, and agitation in nursing home residents with dementia.

It should be noted that most of the measures showed a significant improvement in the targeted symptoms over time. Time effects were observed on the FLACC, CMAI, PANAD, and on the behavioral disturbance subscale of the CSD. Although this finding does not support a difference between AICT and UC, it does show that the residents in the study benefited from a reduction in bothersome symptoms over time. As discussed in the ‘Strengths and Limitations’ section, there was contamination of the UC condition attributable to the crossover research design and the need to be responsive to residents and their families as they were being oriented and engaged in the AICT study.

There are alternative research designs and strategies that would better manage the problem of contamination. One such design would enlist the participation of numerous nursing homes in diverse geographic regions. Units from each of the participating homes would then be randomly assigned to treatment (AICT) or control (UC) conditions. This type of design would require a large number of units and it would be much more expensive to carry out. It is, however, an alternative design that would retain a rigorous, scientific grounding.

Another objective of this study was to evaluate the effectiveness of AICT in increasing residents’ family member’s satisfaction with the care their loved ones were receiving at the two nursing homes. Prior to the start of the AICT intervention (pre-test), the surveys were

completed by family members. These pre-test surveys showed that family members had a positive perception of the homes and were satisfied with the care provided at both facilities. Upon completion of the AICT intervention (post-test), the surveys were once again completed by family members. Family members continued to report a positive perception of the homes and they continued to be satisfied with the care provided. There was virtually no change in the surveys from pre-test to post-test and very little room for significant improvement. In view of these survey results, AICT was not able to improve family member's satisfaction with the care provided at the two participating nursing homes.

A third objective identified at the beginning of this project was to ensure the continuation of the AICT program after the study ended. This objective was only partially realized. The AICT program as a discrete program did not continue at the end of this study although elements of the AICT model were incorporated into the way care teams operated at each facility. For example, a 'five pains' assessment framework was used during the AICT care planning sessions to help identify potential sources of pain for each of the residents participating in the study. These 'five pains' included emotional, familial, physical, psychological, and spiritual pain. Supervisors and direct care staff found this framework to be useful in evaluating residents and in formulating care plans that sought to improve the comfort level and life satisfaction for each of the residents under their care.

The last objective of this project was to develop an AICT Implementation Manual for possible dissemination to other nursing homes in New York State. An eighteen page manual was completed and made available for dissemination in June '05. Staff at the 'New York Association of Homes and Services for the Aging' (NYAHSAs), the 'New York State Health Facilities Association' (NYSHFA), and the 'American Association of Homes and Services for the Aging' (AAHSA) were contacted about the AICT project. The project was described and the availability of the AICT Implementation Manual was communicated to staff at both associations.

After reviewing the AICT Implementation Manual, NYAHSAs has agreed to post it on their website for review and/or downloading by their members. In addition to this, they have agreed to alert their membership about the availability of the manual through their September newsletter. NYAHSAs currently has over 650 nursing homes (not for profit) in its membership base.

NYSHFA was also interested in making the AICT Implementation Manual available to its members through their electronic website. There are currently 350 nursing homes (for profit) that belong to NYSHFA.

The AICT Implementation Manual is currently being reviewed by AAHSA to determine the suitability of this document for dissemination to their membership and the best vehicle for providing this resource to a nationwide audience.

Finally, the AICT Implementation Manual will be made available through the Institute of Gerontology at the University at Albany website. This will be a potentially helpful resource for individuals or organizations that don't belong to the aforementioned nursing home associations.

Table 1. Resident Demographics and Other Descriptive Data

Variable	UC	AICT	Statistic
Age	88.00	84.82	t = 2.561*
Education	11.49	10.96	t = 1.073
Income	\$647.50	\$567.75	t = .184
Mini Mental State	6.80	7.26	t = -.321
Global Deterioration	5.66	5.49	t = 1.089
Activities of Daily Living	7.62	9.04	t = -1.871
Gender (%)			$\chi^2 = 1.182$
Female	98.4	94.7	
Male	1.7	5.5	
Marital Status (%)			$\chi^2 = 3.117$
Married	16.4	8.8	
Single	13.1	19.3	
Separated	0.0	1.8	
Widowed	70.5	70.2	
Race/Ethnicity (%)			$\chi^2 = 1.934$
White	85.0	87.7	
Black	5.0	5.3	
Hispanic	6.7	7.0	
Other	3.3	0.0	
Health Care Proxy (%)			$\chi^2 = 1.490$
No	7.0	14.0	
Yes	93.0	86.0	
Proxy's Relationship to Resident (%)			$\chi^2 = 5.859$
Spouse	10.0	0.0	
Sibling	4.0	4.3	
Child	72.0	72.3	
Other	14.0	23.4	

\* p ≤ .05; \*\* p ≤ .01; \*\*\* p ≤ .001

Table 2. Family Member Demographics

Variable	UC	AICT	Statistic
Age	58.33	58.50	t = -.041
Education	15.80	15.41	t = .506
Gender (%)			$\chi^2 = .010$
Female	63.2	61.8	
Male	36.8	38.2	
Relationship to Resident (%)			$\chi^2 = 5.703$
Spouse	10.5	2.9	
Daughter	26.3	52.9	
Son	31.6	20.6	
Other family	21.1	17.6	
Lawyer	0.0	2.9	
Other	10.5	2.9	
Marital Status (%)			$\chi^2 = .353$
Married	73.3	70.4	
Single	13.3	18.5	
Divorced	6.7	3.7	
Widowed	6.7	7.4	
Race/Ethnicity (%)			$\chi^2 = 1.500$
White	82.3	87.1	
Black	11.8	3.2	
Hispanic	5.9	9.7	
Other	0.0	0.0	

\* p ≤ .05; \*\* p ≤ .01; \*\*\* p ≤ .001



Table 3. Care Recipient Outcomes

Variable	Baseline		8-weeks		Condition	F		
	M	SD	M	SD		Time	Interaction	
<u>FLACC Pain Scale</u>								
Average Pain Over 5 Assessments								
AICT	0.31	0.29	0.24	0.27	0.31	8.39**	0.00	
Control	0.38	0.29	0.30	0.31				
<u>Cohen-Mansfield Agitation Inventory Scale</u>								
Aggressive Behavior								
AICT	1.18	0.47	1.10	0.25	0.48	10.35**	0.06	
Control	1.23	0.48	1.16	0.39				
Physically non-aggressive behavior								
AICT	1.64	1.10	1.30	0.60	1.42	9.96**	4.22*	
Control	1.36	0.52	1.29	0.49				
Verbally Agitated Behavior								
AICT	1.44	0.48	1.28	0.42	0.12	10.97**	1.43	
Control	1.44	0.61	1.36	0.53				

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$

Table 3. Care Recipient Outcomes (continued)

Variable	Baseline		8-weeks		Condition	F		
	M	SD	M	SD		Time	Interaction	
<u>Cornell Scale for Depression in Dementia</u>								
Mood-Related Signs								
AICT	0.28	0.29	0.22	0.30	0.01	3.11	1.12	
Control	0.25	0.27	0.24	0.28				
Behavioral Disturbances								
AICT	0.17	0.20	0.13	0.22	0.50	5.14*	0.11	
Control	0.14	0.20	0.11	0.15				
Physical Signs								
AICT	0.03	0.12	0.02	0.14	1.90	0.02	0.11	
Control	0.01	0.04	0.01	0.06				
Cyclic Functions								
AICT	0.03	0.12	0.04	0.17	2.91	0.23	0.22	
Control	0.00	0.03	0.00	0.03				

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$

Table 3. Care Recipient Outcomes (continued)

Variable	Baseline		8-weeks		Condition	F	
	M	SD	M	SD		Time	Interaction
<u>Cornell Scale for Depression in Dementia (continued)</u>							
Ideational Disturbances							
AICT	0.03	0.20	0.04	0.21	1.98	0.59	0.59
Control	0.00	0.00	0.00	0.00			
Total Depression Score							
AICT	0.11	0.14	0.09	0.17	1.16	1.48	0.13
Control	0.08	0.08	0.07	0.08			
<u>Pain Assessment in Advanced Dementia Scale</u>							
Average Pain Assessment over 5 Days							
AICT	1.64	1.46	1.29	1.45	0.07	5.38*	0.23
Control	1.76	1.38	1.55	1.56			

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$

Table 4. Family Satisfaction Survey

Variable	Time 1		Time 2		Condition	F (df)		
	M	SD	M	SD		Time	Interaction	
FAMCARE Scale								
AICT	86.58	10.46	86.25	12.64	1.98 (56)	0.89 (43)	0.18 (43)	
UC	82.77	13.46	80.89	11.58				
Family Perceptions of Care								
AICT	290.92	36.85	288.21	39.11	3.96 (56)	0.39 (43)	0.02 (43)	
UC	276.34	34.79	271.58	33.40				

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$

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