A descriptive analysis of the problems and interventions observed in care planning for nursing home residents with dementia

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A Descriptive Analysis of the Problems and Interventions
   Observed in Care Planning for
   Nursing Home Residents with Dementia

   By
   Dennis G. Chapman, LCSW-R

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Abstract

This dissertation described and analyzed the problems and interventions used to improve the well-being of 118 nursing home residents with dementia. The problems were identified and interventions were developed during an evaluation of advanced illness care teams at two skilled nursing facilities. All of the identified problems were categorized using a six-dimensional assessment framework. A count of the problems by category and a reliability analysis were carried out to evaluate the usefulness of the six-dimensional model. Medical (primarily pain) and behavior (primarily agitation) problems comprised 64% of all the identified problems. Psychological and psychosocial problems (primarily depression) comprised 16% of all the identified problems. A low frequency of problems in some categories and a Cohen’s kappa of .73 (reliability analysis) provided little support for the six-dimensional model. In respect to interventions, nonpharmacological approaches were used almost twice as much as medications in addressing identified problems. The most effective interventions, as reflected in the highest posttest change ratings, combined medication and social therapeutic support to treat depression. However, these change ratings were not significantly (t=1.88, p=.07) higher than interventions that relied primarily on medications to treat depression in the study population.
Dedication

This dissertation is dedicated to my family who provided love and support throughout the dissertation endeavor.

To the memory of my father, Robert, who clearly articulated the value of education, learning, and individual growth throughout the life span.

To my mother, Ruth, whose innumerable acts of love and kindness supported me throughout my childhood and adulthood.

To my brother, Bob, my sister Linda, and my brother-in-law Doug who offered genuine interest in this work and frequent words of encouragement.

To my sister, Pat, whose generosity of spirit and heartfelt prayers propelled this effort when it seemed to sputter.

To my daughter, Lennay, who is a blessing and a joy. She has been a source of wonder since the day she was born.

Finally, this dissertation is dedicated to Angela, whose unwavering faith and spirit sustained this journey when there was no end in sight.
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Chapter 1

1.1 Introduction

This dissertation will describe and analyze the problems and interventions observed in care planning for 118 nursing home residents with advanced dementia. The care plans were developed as part of a study on Advanced Illness Care Teams (AICTs) carried out by the Institute of Gerontology (IOG) at the School of Social Welfare, University at Albany (State University of New York) during 2004 and 2005. The AICT study was funded by the Dementia Grants Program at the New York State Department of Health in cooperation with the Carmelite Sisters, a faith-based provider of services to aging, infirm populations. The Carmelite Sisters (a.k.a. Carmelite System of Care) operates two New York City skilled nursing facilities, Ozanam Hall of Queens Inc. and St. Patrick’s Home (Bronx), where the AICT study was carried out.

In carrying out this study on AICTs, care plans were developed for each of the 118 residents by the AICTs with IOG staff (Ronald Toseland, Ph.D. – Director; Dennis Chapman, LCSW-R – Graduate Assistant) serving as collaborators. Mr. Chapman, the author of this dissertation, constructed a “Care Plan Review” instrument as a practical tool to identify each resident, to list pertinent diagnoses and medications, and to document and guide the interventions formulated by the AICTs. The Care Plan Review instrument was not an optional or required part of the funded research, but it was an essential tool in the clinical management and tracking of the individualized interventions that were formulated for each of the participating residents. The Care Plan Review instrument also provided critical information in describing and analyzing the interventions.
In describing and analyzing the problems and interventions developed for the 118 nursing home residents participating in the AICT study, five objectives will be addressed. These five objectives provide the basis for this dissertation, and they include:

1. Categorize the types of problems selected to improve the comfort, care, and well-being of residents with advanced dementia.
2. Conduct reliability analysis of the problem categories.
3. Create frequency distribution of the problems in the study population.
4. Identify and classify the interventions used for each problem category.
5. Rate the effectiveness of the interventions in ameliorating the problems.

In addressing these objectives, a more detailed description of what was actually done in the field to improve the comfort, care, and well-being of nursing home residents with advanced dementia will emerge. To improve the comfort, care, and well-being of residents, it is expected that pain, agitation, and depression will need to be managed effectively. The identification of pain, agitation, and depression as common problems in this target population is based on the observations of other researchers in the field (see, for example, Cipher & Clifford, 2004; Cohen-Mansfield & Lipson, 2002; Manfredi et al., 2003). The specific prevalence of these issues is uncertain. It is estimated, for example, that 45 to 83 percent of nursing home residents suffer with pain (Chu, Schnelle, Cadogan, & Simmons, 2004). A detailed description of the problems identified in the AICT study will reveal the prevalence of pain, agitation, and depression in the 118 residents who participated in this study. This will strengthen the linkage between field research and the
theoretical models of assessment that guide the practice of social workers and allied health professionals in the nursing home setting.

In preparing to address the five objectives of this dissertation, a broader contextual picture of aging, dementia, and the role of social work will be explored in this introduction. Trends in aging, nursing home utilization, and a brief description of dementia will be outlined. The roots of social work as a profession and its competing missions of individual treatment and social reform will be summarized along with a brief exploration of issues such as ‘spirituality’ and ‘meaningful activities’ as dimensions that some believe should be an integral part of the biopsychosocial assessment especially in addressing the needs of nursing home residents with dementia. This introduction will conclude with a look at the history of social work in the nursing home setting.

Chapter two will be a statement of problem that establishes the relevance of pharmacological and non-pharmacological interventions as a way to improve the comfort, care, and well-being of nursing home residents with advanced dementia. This will include a review of the literature with an emphasis on non-pharmacological interventions used in nursing homes with this population. Chapter three will describe the qualitative and quantitative methods used to address each of the five objectives outlined above. Chapter four will cover the results of the analyses including a descriptive summary of interventions used in the AICT study. Chapter five will be a discussion of the results observed for each of the five objectives with recommendations for social work practice in general as well as with nursing home residents with advanced dementia.
1.2 Aging, nursing home utilization, and dementia

During the past century, life expectancy in the United States has increased dramatically. In 1900, the average life span was 48 years and by 1990 it had increased to 76.5 years (Yang, Norton, & Stearns, 2003). In 2006, life expectancy reached an all-time high of 78.1 years (Heron, Hoyert, Xu, Scott, & Tejada-Vera, 2008). This increase in longevity is attributable to numerous factors including improvements in nutrition, living and working conditions, acute care medicine, medical technology, pharmaceuticals, public health education, and a growing base of knowledge in medicine and related disciplines. One author has described this increasing longevity as a “social avalanche” in which the fastest growing age group is ‘seniors’ over the age of 85 (Callahan, 1987, pp. 20-21). This social avalanche is reflected in population statistics over time. In 1900, 4.1% of the populace was over 65 and, by 1984, this figure had almost tripled to 11.9% (p.232). In 1985, people over 65 outnumbered those under the age of 18 for the first time in American history.

One health related consequence of increasing life spans is the increase in age-related diseases and disabilities. These diseases and disabilities include cancer, visual and auditory impairment, cardiac insufficiency, pulmonary diseases, vascular restrictions, and dementia. As noted in the Introduction, this dissertation will focus on the age-related disease of dementia, especially as it advances in residents of nursing homes. It should be noted that Alzheimer’s disease is an advanced form of dementia, and that these two terms are often used interchangeably. In view of this, what exactly is dementia and what are the impairments and disabilities that are observed in this disease?
Dementia has been defined as a “syndrome of acquired and persistent impairment in cognitive and intellectual functioning” (Schuster, 2000, p.373). The DSM – IV (Diagnostic and Statistical Manual of Mental Disorders, 2000) describes dementia as “the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning” (p.148). *Aphasia* refers to the deterioration of language and communication skills to the extent that content of speech may be overly vague, empty, and lacking in meaning. *Apraxia* is the inability to carry out simple motor activities such as combing hair or brushing teeth even though there is the physical capacity to carry out these tasks. *Agnosia* is the inability to recognize (through visual or tactile senses) people, places, and things that should be familiar. This loss can include the failure to recognize family members and the inability to recognize one self in the mirror. The *disturbance in executive function* means that the ability to plan, initiate, and think abstractly have been impaired. This may be evident in the individual’s inability to learn and carry out new tasks or to carry out abstract activities such as budgeting.

In reviewing these impairments and deficits to cognitive functioning, it is clear that individuals with advanced dementia need round-the-clock care and supervision. It is also important to note that dementia is a terminal disease. This is often forgotten or overlooked because dementia progresses over years and has an indeterminate end. This is one of the reasons why hospice is generally not used when dementia, accompanied by age-related disabilities, is the primary diagnosis. As a result, nursing homes are the last destination for most individuals with advanced dementia or Alzheimer’s disease, and that is where they will die (Mitchell, Teno, Miller, & Mor, 2005).
Given the growing senior and oldest-old (+85 years) population and the increasing prevalence of dementia as a chronic condition of aging, one would expect an increase in the utilization of long-term care facilities i.e. nursing homes. This expected demand for skilled nursing facilities has not materialized, and the rate of occupancy in these facilities has actually dropped from 92% in 1985 to 84% in 2001 (Centers for Medicaid and Medicare Services. Retrieved on June 10, 2007).

Why has the utilization of nursing homes been declining during a period in which an increase in the elderly population and an increase in the chronic conditions of aging have been observed? There are at least three reasons for this. According to Vourlekis & Simon (2006), there has been:

1) a decline in the severity of disability among older adults,

2) an increase in the use of home health services, and

3) competition from the assisted living industry

This reduced utilization in nursing home care may be unexpected good news, especially in view of the growth in the senior population, but it has been offset by an increase in the severity of illnesses in those individuals needing this level of care. For example, from 1991 to 1997 nursing home residents requiring total care (i.e. bedfast) increased from 3.5 to 7.2% (Harrington & Carrillo, 1999). During the same period, residents with dementia increased from 34.7 to 41.7% and those with depression increased from 9.3 to 12.4%.

Though nursing home utilization is not expected to increase dramatically in the future, the number of nursing home residents with dementia is expected to grow. Between 2000 and 2050, the number of people with Alzheimer’s disease is projected to almost triple from 4.5 to 13.2 million (Hebert, Scherr, Bienas, Bennett, & Evans, 2003).
As dementia advances, the care demands overwhelm care providers as round-the-clock care becomes necessary. When round-the-clock care is required, skilled nursing facilities are frequently the only option left for beleaguered care providers.

1.3 The roots of social work and its competing missions

Social workers have struggled for over 100 years to establish their professional legitimacy as effective helpers and agents of change. They have provided advocacy, education, empathy, information, emotional support, validation, and an array of services to individuals in need. In addition to the provision of services to individuals, social workers have spearheaded movements to bring social justice to oppressed, marginalized and powerless populations. This focus on both individual need and social justice has been characteristic of social work since its birth in the late 19th century. However, these two missions have not always enjoyed a peaceful coexistence. In fact, there has been a long-standing debate about the true mission of social work, and this has been part of the struggle to establish social work as a legitimate profession.

This disagreement about the mission of social work has occasionally erupted in the social work literature. Should social work’s primary emphasis be on helping individuals to adapt/cope with life circumstances? Or should social work be promoting change and social action in the local community and society? These two ends are often seen as competing and antagonistic. One social work author has framed the conflict in terms of social reform versus individual treatment and referred to these two perspectives as ‘the one hundred year debate’ (Haynes, 1998). Another social work writer described this schism in an article titled “Still between client and community” (Hartman, 1988). Still others have characterized social worker/psychotherapists as ‘unfaithful angels’ who
have abandoned the profession’s commitment to social change -- the true mission of social work (Specht & Courtney, 1994).

The continuing debate about social work’s mission is not always cast in polarizing terms. While the individual and social missions are disparate, they frequently overlap and are simply part of a broader concern about the well-being of individuals and society. This perspective has been voiced by social work scholars who take a more accommodating stance. For example, one scholarly group has observed that the profession’s main objective is to work towards “the enhancement of individual and social well-being” (Meinert, Pardeck, & Krueger, 2000, p. 7). The National Association of Social Workers Code of Ethics provides further support for this view of social work in asserting that the “historic and defining feature of social work is the profession’s focus on individual well-being in a social context and the well-being of society” (National Association of Social Workers, 1999).

This dual focus in social work can be traced back to the settlement house and charity organization society (COS) movements that took root in large cities during the last few decades of the 19th century. Settlement houses were “an institutionalized form of self-help for” poor urban immigrants who were having difficulty, economically and socially, adapting to life in America (Reisch, 1998, p. 166). In 1889, Jane Adams established one of the first settlement houses in the United States (Hull House in Chicago) and, by 1910, there were over 400 settlement houses operating in the urban centers across the country (Stein, 2001). Settlement house workers were often well-educated and offered English language classes, vocational training, counseling, and daycare for working immigrant parents. These early social workers were politically
active and lobbied for improvements in public sanitation, living conditions in crowded tenements, and unsafe work environments. Social reform, self-help, and group work activities are important aspects of social work that began in the settlement houses.

The social work profession also has roots in the work carried out by the Charity Organization Societies (COS). The COS was created to unite and coordinate local charities rather than provide material goods and services. By working together, local charities could distribute aid in an equitable, rational manner (Leiby, 1997). This coordinated approach was called “scientific charity”, and its philosophical assumption was that personal shortcomings were at the root of poverty (DiNitto, 2000, p. 334). The COS would use friendly visitors to investigate the circumstances of each poverty-stricken family or individual who was brought to the attention of the COS. This examination of each situation in an organized, methodical way came to be known as ‘casework.’. This approach evolved into psychiatric social work and other forms of treatment for individuals and families.

As part of this effort to more effectively organize charity, there was a call for standardization and efficiency in carrying out casework/social work activities (Reisch, 1998). To develop a more efficient, standardized approach to casework, the physician’s professional practice was used as a model. As this model gained acceptance for social work practice, there was a growing consensus that the function of caseworkers was ‘to rehabilitate.’ A good caseworker, like a good doctor, would find that “diagnosis and treatment went hand in hand with rehabilitation” (p. 165). This model of practice found expression in Mary Richmond’s (1917) seminal book, “Social Diagnosis”, which laid the ground work for a more scientific social work method and stressed the importance of
assessment in formulating a diagnosis and plan of treatment. This conceptualization of
social work clearly emphasized helping individuals rather than reforming society.

Although social work’s two missions have contributed to an ambiguous or diluted
identity, this identity has also been blurred by the range of activities and the variety of
methods used in social work practice. For example, an eco-systems perspective is
commonly used in social work, but it does not define the profession or give it a coherent
identity (Wakefield, 1996.). This is further compounded by divergent treatment
philosophies that may be strictly behavioral in one setting and psychodynamic in another.

Given these divergent approaches to social work practice, the call for evidence-based
practice, best practice models, and research utilization is understandable. In spite of the
variety of practice orientations in social work, the profession has survived and social
workers have become recognized as important service providers in child welfare,
education, healthcare, mental health, and social services. The wide array of social work
practice settings and the adaptive nature of the profession have helped it survive.

Unfortunately, the survival of the profession has come at the expense of a coherent
identity.

Further evidence of social work’s ability to survive through adaptation can be
seen in the important, influential roles social workers have taken on in host settings
(Dane & Simon, 1991). Social workers have established their credibility in hospitals,
schools, clinics, rehabilitation centers and nursing homes. In these settings, social
workers are often the minority profession (i.e. ≤ 15% of the professionals practicing at a
particular site, p. 209) and, as such, their practice is closely scrutinized. In spite of this
minority role and the accompanying scrutiny, the specialized skills and expertise of social
workers have been recognized by other professionals in host settings. This recognition can be seen in federal legislation that has mandated social work services in Medicare certified nursing homes (Omnibus Budget Reconciliation Act, 1987). Another legislative action that validates the role of social work is the allocation of federal funds to support social work education for child welfare staff working in local child protective services (Behrman, Rizzo, Mancini, Briar-Lawson, Baskind, & Valentine, 2006). In addition to this, New York State law has identified social work as one of three professions (along with medicine and psychology), that is qualified to serve in ‘Director of Community Services’ positions in counties throughout the state. These are key leadership roles in Local Governmental Units that oversee the funding and provision of services in the mental health, mental retardation and developmental disabilities, and alcohol and substance abuse services systems in the local community.

The specialized skills that social workers bring to their practice include an understanding of how individuals interact with their social environment. As noted above, an eco-systems perspective, which draws on systems and ecological theory, is often used by social workers to inform and guide the history-building and assessment process. The appeal of an eco-systems approach is that it provides a way to understand individuals in reciprocally influential processes as they “engage in transactions with other humans and with other systems in the environment” (Hepworth, Rooney, Dewberry Rooney, Strom-Gottfried, & Larsen, 2006, p.17). Although many social workers find the eco-systems perspective useful in practice, it is “not a substantive theory or model that makes specific empirical claims” (Wakefield, 1996, p.6) and, therefore, has limited usefulness in defining, integrating, and enhancing the credibility of social work as a profession.
Another common approach to social work practice, especially in the assessment of individual functioning, finds practical and theoretical usefulness in a three-dimensional framework i.e. biological, psychological, and social dimensions. This has, historically, been referred to as the psychosocial perspective (Woods & Robinson, 1996). In recent decades, the more descriptive ‘biopsychosocial assessment’ has been used to reflect the biological dimension in the psychosocial assessment. This multidimensional conceptualization is a general approach to assessment that has become the hallmark of social work in a variety of practice settings. The biological, psychological, and social dimensions of human functioning are very broad and general, which allows them to be applied to a variety of populations. In her seminal work on long-term care of older people, Elaine Brody (1977) echoed this social work perspective by asserting that the goal of a responsible society should be the promotion of optimal human functioning in the physical, social, and psychological spheres. But are these three dimensions the best framework for special populations such as nursing home residents with advanced dementia, or should other dimensions be added to the framework?

Some gerontologists believe that ‘meaningful activities’ (Volicer and Bloom-Charette, 1999) and ‘spirituality’ are significant dimensions that need to be routinely assessed in aging populations. Volicer and Bloom-Charette propose a three-dimensional assessment framework that addresses medical and psychological issues, along with meaningful activities, in working with individuals with advanced dementia. They assert that these individuals often end up in long-term care facilities and need to be engaged in activities that reflect their interests and draw on their strengths and abilities (p.8). These long-term care residents need more than usual nursing home care and they need more
than short periods of specialized programming. They benefit from ongoing work on household tasks and activities of daily living. Volicer and Bloom-Charette characterize these every day tasks as meaningful activities.

Spirituality, which has been defined as “the search for meaning, purpose, and morality” (Nelson-Becker, Nakashima, & Canda, 2006, p.798) is closely aligned with meaningful activities. The recognition of spirituality as a significant dimension in the assessment of individual functioning dates back at least fifty years. In 1957, the journal Social Casework published an article on religious and spiritual values in social work practice (Spencer, 1957). Ten years later, another social work writer observed that social workers needed to understand the moral and spiritual aspects of clients (Solomon, 1967). In 1996, Au-Deane S. Cowley reiterated that the spiritual dimension has been neglected in the multidimensional assessments carried out by social workers (Cowley, 1996, p.663). Over the years, social workers have had an enduring interest in spirituality and there have been repeated calls to examine this important facet of the individual.

In returning to the similarities between ‘meaningful activities’ and ‘spirituality’, it should be noted that Volicer and Bloom-Charette view meaningful activities as action-oriented, and they don’t address spirituality as a potentially significant part of this dimension. In spite of this, it is easy to see how the search for meaning and purpose could bring individuals to activities that are both meaningful and spiritual. Consider faith-based initiatives such as ‘Habitat for Humanity’, which rely on volunteers to build and/or rehabilitate houses for poor families. These volunteers often find this work to be meaningful and, given the religious affiliation of many volunteers, there is certainly a spiritual aspect in this work for them. Although ‘meaningful activities’ and ‘spirituality’
may differ in some respects, there are striking similarities that suggest they are part of a single domain that captures individual values, beliefs, motivation, and a sense of purpose or satisfaction in life. Does the prevalence and importance of these factors justify the addition of a ‘meaningful activities/spirituality’ domain to the biopsychosocial assessment? This is one of the questions that will be addressed later in this dissertation.

1.4 Social work and the nursing home setting

The history of social work has much in common with the history of nursing homes. Both have roots in the poor laws, poor houses and parish relief (Kane, 2006). Nursing homes, like orphanages, inebriate asylums, and ‘mad houses’, evolved as a response to the problems of indigence, disability, and homelessness. The nursing home became a practice setting where social workers could fulfill both missions (direct practice and social justice) of social work. In this setting, social workers could help care for the disabled and marginalized residents while advocating for more humane treatment of these residents through institutional change and regulatory reform. Today, nursing homes are regulated and licensed to provide a range of services such as long-term care, short-term rehabilitation, and specialized dementia care. In addition to these improvements, many homes provide these services in home-like environments in an effort to mitigate the trauma of institutionalization.

In respect to individual care, social workers participate on interdisciplinary teams that plan care, problem-solve, make policy and procedural recommendations, and implement/oversee program initiatives that impact each resident’s life at the nursing home. Social workers usually take the lead in working with the resident’s family and friends. They make referrals, plan for discharge, and often carry out educational and
therapeutic activities. Most importantly, social workers construct a comprehensive resident history, including a multidimensional assessment, to inform the team’s care planning. As noted in the preceding section, this multidimensional assessment is often referred to as the ‘psychosocial’ or ‘biopsychosocial’ assessment.

The other social work mission, social reform, has played an important role in long-term care, bringing about substantial improvements in the nursing home industry. Calls for regulatory reform and advocacy on behalf of nursing home residents have been taken on by several social work activists during the last half of the 20th century. During the ‘60s, Herbert Shore, who was a nursing home administrator and social worker, emphasized the importance of individualizing and humanizing the nursing home environment (Kane, 2006). In the ‘70s, Elaine Brody wrote her seminal book on long-term care to “ease the stresses” (Brody, 1977, p.305) associated with placement of older individuals into institutional settings. During the ‘80’s and subsequent decades, Carter Catlett Williams advocated for more humane treatment of nursing home residents. For Williams, more humane treatment means less reliance on medications to control or manage agitation and unruly behavior in residents who may be experiencing pain, frustration, and a sense of loneliness or loss.

The advocacy of these social workers has improved the quality of care that nursing homes provide to their residents. Shore’s ideas presaged the ‘culture change’ movement which seeks to humanize and individualize the care of residents by encouraging social contact and allowing the preferences and opinions of residents to guide the care that they receive. The culture change movement has been given expression through innovative projects such as the Eden Alternative (Thomas, 1999) and
By its more recent iteration, the Green House Concept (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). The Eden Alternative is an approach to long term care that strives to eliminate the dehumanizing aspects of institutional care by creating a warmer, more accommodating physical environment and by giving residents and their families more influence in the way that care is delivered.

The Green House Concept develops the Eden Alternative further and calls for a radical transformation of the traditional nursing home culture and organization of staff. This transformation envisions the creation of small caring communities in self-contained homes with no more than 7 to 10 elders in each home. These “Green Homes” provide private rooms and baths for each resident and eliminate the ubiquitous ‘nursing station’ as the hub of organization and control. Doctors, nurses, social workers and other health professionals continue to provide care to residents but this care is provided on a more personal and smaller scale than in traditional institutional settings. The Green House Concept and Eden Alternative both emphasize the importance of individualizing care as a means to reduce boredom, loneliness, and the lack of meaning in the lives of nursing home residents.

Elaine Brody, a geriatric social worker and scholar, authored a landmark book on long-term care three decades ago (Brody, 1977). In this book, she steadfastly affirmed the social work values of autonomy, respect, and self-determination in working with aging individuals. She also identified and put into practice the ‘strengths-based’ assessment that challenged problem-oriented perspectives in working with elderly, disabled individuals. For example, Brody considered the aggression observed in many nursing home residents as a healthy sign – a life-prolonging strength. She believed that
this aggressive behavior often reflected the resident’s will to live, rather than simply bad behavior to be controlled or eradicated. Strengths-based approaches to care have been adopted in other populations and programs including family preservation services that try to avert out-of-home placement of ‘at risk’ children, and substance abuse services that strive to improve outcomes for addicted individuals (Saleeby, 2006).

Carter Catlett Williams has been the most recent social work reformer in long-term care. She has worked with others to restore “meaning and life satisfaction to the lives of frail elders” through culture change in long term care and in the larger community (Lustbader & Williams, 2006, p. 651). Williams has also worked to reduce or eliminate the use of powerful antipsychotic medications as the preferred method to manage disruptive, unruly behavior of nursing home residents. The use of ‘chemical restraints’ i.e. sedating medications, to control the behavior of nursing home residents made life easier for nursing home staff but clearly diminished the quality of life for residents and their families as they dealt with disabling illnesses, an institutional living environment, and end-of-life issues. The result of Williams’ activism, as well as others working to improve resident care, was the passage of The Nursing Home Reform Act of 1987 (Omnibus Budget Reconciliation Act, 1987). This federal legislation prohibited the use of chemical restraints to control the behavior of nursing home residents, and established regulatory requirements to improve the quality of care in the nursing home industry.

This introduction has described the two missions of social work and how both missions have played a part in the operation and evolution of nursing homes. More specifically, social workers have been involved in the ongoing care of nursing home
residents and they have been advocates for reform in the nursing home industry. This
dissertation will focus on the individual care, rather than the social reform, mission of
social work, and it will analyze the care plans and interventions that social workers and
other allied health professionals provided to nursing home residents with advanced
dementia during a recent research study. The care plans and interventions were
developed for residents at two New York City nursing homes during 2004 and 2005 as
part of a study funded by the New York State Department of Health Dementia Grants
Program.

During this study, Advanced Illness Care Teams (AICTs) were formed at both
nursing homes, and these multidisciplinary teams formulated the care plans for each of
the residents participating in the study. Each care plan specified at least one target
problem, and interventions were then developed in response to the targeted problem.
Social workers were key members of these teams but the specific interventions were
often implemented by other team members as well as an array of staff working to provide
‘round the clock’ care. The staff providing this care included doctors, nurses, nurse
aides, social workers, pastoral care staff and other professionals working at the two
nursing homes. Through an analysis of these identified problems and interventions, it is
expected that a better understanding of how social workers and other health professionals
try to improve the comfort, care, and well-being of residents with advanced dementia.
Chapter 2

2.1 Statement of problem

As longevity in the United States has increased, the incidence and prevalence of Alzheimer’s disease, vascular dementia, and other dementing illnesses has increased dramatically in both community and nursing home settings. For example, it is estimated that there were between 2.9 and 4.5 million people with Alzheimer’s disease in 2000 and, by 2050, the prevalence of this disease is projected to affect 13.2 million people (Bernstein & Remsburg, 2007; Hebert, Scherr, Bienas, Bennett, & Evans, 2003). The challenge of providing appropriate, effective care for this growing segment of disabled, terminally ill individuals will fall increasingly to nursing homes because, as one recent study confirmed, the majority (66%) of dementia-related deaths occur in this setting (Mitchell, Teno, Miller, & Mor, 2005). Since people do not recover from dementing illnesses, appropriate care often involves measures that promote comfort, manage pain, and foster a sense of well-being.

Improving the comfort, care, and well-being of nursing home residents with dementia is a national health care goal that has been promulgated through federal law and through the recommendations of professional associations. The Nursing Home Reform Act of 1987 mandated that nursing home residents have the right to;

1) An environment that promotes quality of life, including physical, mental, and psychosocial well-being, and

2) Freedom from chemical and physical restraints for the purpose of behavior management (Beck et al, 2002; Omnibus Budget Reconciliation Act, 1987).
The American Geriatrics Society and the American Association for Geriatric Psychiatry have also made recommendations to improve the mental health care that nursing home residents receive (Snowden, Sato, & Roy-Byrne, 2003). These requirements and recommendations for improving nursing home care were intended, in large part, to benefit the growing number of individuals with dementia who constitute the majority (50-80%) of the nursing home population (Payne et al, 2002; Magaziner et al, 2000).

In this population of nursing home residents with a dementing illness, improving care often involves treating pain, depression, and agitation. Pain is a common problem in this population and, although it is common, it is often underreported and undertreated (Hutt, Pepper, Vojir, Fink, & Jones, 2006). Depression is another commonly observed problem that occurs in tandem with agitation in demented nursing home residents (Bartels et al, 2003; Heeren et al, 2003). Agitation covers an array of behaviors such as wandering, repetitive comments, questions, and mannerisms, screaming, calling out, spitting, hitting, cursing, and kicking (Cohen-Mansfield, Marx, & Rosenthal, 1989). Agitated behavior can endanger residents and upset the social milieu/environment which is central to the sense of order, safety, and trust in the staff’s ability to provide quality care in the nursing home.

In addition to these issues of pain, agitation, and depression, there is the challenge of treating an array of symptoms concurrently. Specifically, improving the care of nursing home residents with dementia almost always involves multiple targets or problems to be addressed through the collaboration of professionals from different disciplines e.g. nursing and social work. To achieve this end, and to meet care planning requirements prescribed by Medicaid and Medicare, most nursing homes use an
interdisciplinary team approach. An interdisciplinary team in the nursing home setting usually includes physicians, nurses, nursing assistants, social workers, and allied health professionals such as dieticians, and occupational and physical therapists. Therefore, improving the functioning of the interdisciplinary team is one approach to improving the care provided to residents.

Another way to improve the care received by nursing home residents with dementia is to assess and address any pain issues that are identified. Pain is one of the most common problems in this population. It is estimated that 45-83% of nursing home residents regularly suffer with pain (Chu, Schnelle, Cadogan, & Simmons, 2004), and the problem of inadequate pain treatment for nursing home residents with dementia has been a recurrent theme in the literature (Cohen-Mansfield & Lipson, 2002; Nygaard & Jarland, 2005; Won et al, 1999). In addition to the humane concerns this issue raises, inadequately treated pain has been associated with depression (Cipher & Clifford, 2004; Parmalee, Katz, & Lawton, 1991), agitation (Buffum, Miaskowski, Sands, & Brod, 2001; Manfredi et al, 2003), and a reduced level of activity and socialization (Chibnall, Tait, Harman, & Luebbert, 2005). These studies point to the prevalence of pain and other associated symptoms in nursing home residents. Residents with a dementing illness pose an additional challenge because the impairment in their cognition and communication makes it difficult to accurately assess their comfort and well-being.

2.2 Study on the effectiveness of Advanced Illness Care Teams (AICTs)

AICTs are multidisciplinary teams that hold the promise of improving the comfort, care, and well-being of nursing home residents with advanced dementia. During 2004 and 2005, the Institute of Gerontology at the School of Social Welfare, University
at Albany (State University of New York) carried out a study on the effectiveness of AICTs in caring for this population. This project was funded by the New York State Department of Health, Dementia Grants Program, and sponsored by Ozanam Hall of Queens Inc. nursing home. St. Patrick’s Home, another nursing home in a neighboring borough (Bronx), also participated in this project as Ozanam’s sister facility. Both homes are skilled nursing facilities operating under the auspice of the Carmelite System of Care, a faith-based health care provider with operations as far west as Iowa, and as far south as Florida. Ozanam Hall is located in a mixed residential-commercial neighborhood and has a capacity of 432 residents. St. Patrick’s Home is also in a mixed residential-commercial neighborhood and has a capacity of 264 residents.

The AICT study identified 60 residents at Ozanam and 60 residents at St. Patrick’s with advanced dementia who consented, usually through a family health care proxy, to participate in the AICT study. The total number of participants in the study dropped from 120 to 118 when two residents from Ozanam were withdrawn from the study and two replacement residents were not immediately available. To ensure that all participants had advanced dementia, residents were screened using three standardized instruments: (1) the Mini Mental State Examination (MMSE: Folstein, Folstein, & McHugh, 1975), (2) the Global Deterioration Scale (GDS: Reisberg, Ferris, de Leon, & Crook, 1982), and (3) the Activities of Daily Living Scale (ADL: Luchins, Hanrahan, & Litzenberg, 1998). All of the residents who qualified for the study needed assistance on four or more ADLs, scored 23 or lower on the MMSE (0-30 point scale), and had cognitive impairment equivalent to Stage 4,5, 6, or 7 on the GDS. In addition to these criteria, residents had to have a diagnosis of Alzheimer’s disease or some other form of
dementia, and had to have family members or friends with power of attorney to sign consent forms authorizing their participation in the study. Residents with serious emergent medical conditions (e.g. aspiration pneumonia, difficulty swallowing, dehydration, or decubitis ulcers) were excluded from the study because these conditions required immediate treatment.

During the 8 week intervention, the AICT met five times (week 1, 2, 3, 5, 8) to develop, implement, and monitor care plans for each of the residents participating in the AICT study. The AICTs were comprised of staff working in each of the participating units at the two nursing homes. Team members included those from the disciplines of: medicine, nursing, social work, psychology, physical and occupational therapy, and nutrition. Residents and their families were invited to participate in a planning meeting that was usually scheduled for the third week of the intervention. They were also invited to participate in a final, wrap-up meeting during the last week of the intervention period.

The AICT planning meetings were held to brainstorm and collaboratively develop individualized care plans for each of the participating residents. The goal in all of these activities was to improve the comfort, care, and well-being of the residents. The principal investigator, Ronald W. Toseland, and the author (Dennis Chapman) of this dissertation served as team members and consultants for the AICTs. Dr. Toseland and Mr. Chapman are both experienced, licensed clinical social workers, and they provided in-person or telephone supervision during the AICT meetings.

The hypothesis for the AICT study was that residents randomized to the AICT intervention would experience statistically significant (p < .05) reductions in pain, depression, and agitation compared to residents who were assigned to the control (usual
care) condition. Standardized measures were used to quantify pain, depression, and agitation. These measures are shown below.


Depression: Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoian, 1988).


These measures were administered prior to (pretest) the AICT intervention and at the conclusion (posttest) of the 8-week intervention period. The 8-week intervention periods were implemented sequentially with enrollment of residents into treatment cohorts. This was done to reduce the burden of treating 118 residents during a single intervention period. The sequential implementation was also well-suited to the crossover research design which used residents awaiting treatment as controls for the treatment condition.

The data from the outcome measures was analyzed using random effects regression models (RERMs) and t-tests. The RERMs produced condition x time interaction results that revealed significant differences between AICT and usual care. Specifically, during the 8 week intervention period, the residents in AICT experienced a significantly greater decrease in physically nonaggressive behaviors (e.g. pacing, repetitive vocalizations) compared to residents in usual care. AICT residents also had a
greater reduction in aggressive and verbally agitated behaviors compared to the usual care group but this difference was not statistically significant.

The t-tests were used to compare the pretest and posttest scores of all the residents after completing the AICT intervention. These scores showed significant reductions on all of the pain and agitation scales during the 8 week intervention period. There was also a significant reduction on the behavioral disturbance subscale of the CSDD but the other four subscales of this depression measure did not show significant change over time. Overall, the analyses of the outcome measures provide some support for the hypothesis that residents assigned to the AICT intervention would experience statistically significant reductions in agitation, pain, and depression compared to residents assigned to usual care. In this study, AICT did produce statistically significant decreases in physically nonaggressive agitation compared to usual care. In addition to this, exposure to the AICT intervention did result in statistically significant reductions in all three agitation subscales and both pain scales, but not the depression scale.

2.3 Assessment frameworks used in the AICT study

In the AICT study described in the preceding section, multidisciplinary teams developed individualized plans of care for nursing home residents with advanced dementia. In developing these individualized plans, the AICTs used assessment frameworks that shifted to meet the needs of each resident. From the beginning of the project, these frameworks were described as holistic i.e. the frameworks tried to capture aspects and features of the whole person. For example, the primary assessment framework used in the AICT study addressed four domains of care: (1) medical/physical issues, (2) meaningful activities, (3) psychological problems, and (4) behavioral
concerns. Another framework that was used, albeit less frequently, addressed five domains of interest: (1) physical, (2) emotional, (3) psychological, (4) spiritual, and (5) familial. In yet other instances, the traditional biopsychosocial framework addressing three domains (biological, psychological, and social) was able to fully capture significant aspects and features of the resident and his or her unique circumstances. It should be noted that although advanced care planning (advance directives, health care proxies, power of attorney, etc.) is another important part of a holistic approach to improve advanced illness care for nursing home residents, it was not included in the AICT care plans. Advanced care planning was not addressed by the AICTs because both of the participating homes thoroughly address this issue during the admission and care planning process, and both homes update plans for each resident on a regular basis.

Throughout the AICT project, the use of assessment frameworks was revisited by the author as a personal research interest and as a clinical tool in the development of individualized care plans. As described in the Chapter 1 Introduction (Section 1.1) of this dissertation, the author created a “Care Plan Review” instrument to guide, monitor, and document the AICT plan of care for each resident. As each plan was being developed and recorded on the Care Plan Review, the assessment framework would sometimes shift to meet the perceived needs of the resident. For some residents, spiritual concerns were very important but, for others, meaningful activities were more important, and the opportunity to participate in certain kinds of activities brought a sense of purpose that had been lost in their move to the nursing home. Assessment frameworks were instrumental in understanding the preferences and unique life circumstances of each resident and they helped to guide care plan development during all of the intervention periods. Given the
usefulness of these frameworks in developing care plans, the author believed they could also be useful in describing and organizing all of the problems addressed in the study population during the course of the AICT project.

The author had numerous discussions with IOG staff about how well the assessment frameworks described, or matched up with, the problems specified on the care plans. Could these frameworks be used to describe and categorize all of the problems addressed in the AICT interventions? How many domains should be used to adequately describe and organize the problems? These discussions had a practical, problem-solving orientation but they resembled a grounded theoretical approach in the way that the abstract assessment frameworks were compared, or fit, to the data collected on the care plans. For example, it was decided that a psychosocial category or domain would be useful to capture those interventions where a problem such as depression was treated with an antidepressant medication and some form of social treatment/activity. Individual cases were reviewed to confirm that psychosocial categories and interventions were used fairly regularly, not just episodically, in the study population. In this case review activity, the assessment frameworks were being grounded in the data collected in the Care Plan Reviews. This approach is similar to grounded theoretical methods that involve inductive, comparative, and iterative strategies to forge a connection between theoretical ideas and the data that informs these ideas (Charmaz, 2006). These methods are used to develop or corroborate theory by grounding the abstraction and generalities of theory in data.

Through these inductive, iterative case reviews and discussions on assessment frameworks, numerous domains/categories were identified. The four domains of
medical/physical, meaningful activities, psychological, and behavioral were identified as the basic assessment framework. These four dimensions were central to the AICT holistic view of care and they were used during the planning and implementation stages of the AICT study. Several other dimensions including family, spirituality, psychosocial, and emotional were used at different times in developing the individualized care plans for the residents participating in the study. Should any of these dimensions be added to the basic assessment framework? Should any of the dimensions from the basic framework be omitted or combined with another dimension?

During these discussions on what assessment framework would work best for describing and categorizing the AICT problems, it was decided that the basic framework with four domains (medical/physical, meaningful activities, psychological, and behavioral) should be used. This basic framework was present at the beginning of the study and it was relevant throughout the care planning process. This was evident in sampling the data in the Care Plan Review forms which confirmed that numerous problems could be categorized in each of the four domains of the basic assessment framework. But what about the other dimensions that were used at different times to assess the needs of residents?

In considering what dimensions should be added to the basic assessment framework, it seemed that meaningful activities and spirituality were closely related, overlapping domains. Although they are similar, meaningful activities is a broader, more general domain than spirituality. Spirituality fits within the meaningful activities domain but meaningful activities does not always fit within a domain of spirituality. This difference can be seen in the Care Plan Reviews of two cases from the AICT study. For
one resident, attending mass filled a spiritual need, and this could fit in to a spiritual or meaningful activities category. Another resident enjoyed folding laundry as a way to contribute to the work on the unit. This activity could also fit in to a meaningful activities category, but it would not be accurate to describe the activity of folding laundry as spiritual. In view of this difference, it was decided that spirituality should be part of the meaningful activities domain rather than a separate domain.

The dimension of emotional was part of an alternative assessment framework that was used occasionally in the AICT project and, therefore, it was considered as an addition to the basic assessment framework. This dimension, however, was too amorphous and never really contributed to the assessment and care planning process. In addition to this, any problems that were considered emotional seemed to fit better within the psychological or psychosocial domain. In view of this, emotional was eliminated as a dimension that might enhance the basic assessment framework.

Two other dimensions were considered as possible enhancements to the basic assessment framework; family and psychosocial. A family dimension was considered because families were an integral part of the AICT intervention. Families gave consent for their loved ones to participate in the AICT study. Families were routinely invited to participate in care planning meetings, and their perspective on improving the care provided to their family member was sought. As a result of these factors, the family dimension was added to the basic assessment framework.

The psychosocial dimension was considered as an addition to the basic framework because it characterizes a social work perspective on assessment. Although it is a single dimension, it combines the psychological and social factors that are often
intertwined and inseparable in human development. It was also the only dimension that explicitly addressed social factors in arriving at a truly balanced, holistic assessment. For these reasons, the psychosocial dimension was added to the basic assessment framework.

With the addition of the family and psychosocial dimensions to the basic assessment framework, a six dimensional assessment framework was created to describe, categorize, and analyze the problems addressed in the AICT study. This six dimensional framework was created as part of the author’s dissertation and was not a required or optional element in the funded AICT project. The six dimensions, which will serve as a guide in the categorization of problems documented in the Care Plan Reviews, are listed below along with a brief description.

1) Medical/physical – this area is comprised of physiological problems, such as pain, that are often treated through medical/pharmacological interventions.

2) Psychological – this area covers psychiatric disorders and symptoms, such as depression, paranoia, hallucinations, and delusions.

3) Psychosocial – this area includes problems with psychological and social aspects, such as grief or social isolation accompanied by depression.

4) Behavioral – this area covers an array of actions or behaviors, such as agitation, wandering, screaming, and hitting.

5) Meaningful activities – this can include a variety of activities that an individual finds engaging, entertaining, purposeful, or intrinsically valuable.

6) Familial – this includes issues of loss, guilt, conflict, support, and education in respect to nursing home residents and their family.
A literature review of nursing home intervention studies that relate to each of these six categories is presented in the sections to follow. The chapter will conclude with an additional review of the literature on interdisciplinary team interventions to improve the well-being of nursing home residents with dementia.

2.4 Nursing home intervention studies

There have been numerous studies about intervening with nursing home residents with dementia, depression, and agitation, along with other behavioral symptoms. A recent search of MEDLINE, Psyc Info, and Social Work databases using the terms ‘nursing home’, ‘dementia’, and ‘behavior’ resulted in over 1,400 matches. Refining the ‘behavior’ search term to ‘behavioral interventions’ resulted in fewer matches but there have still been hundreds of studies over the past thirty years that have focused on the behavioral (agitation, yelling) and psychological (primarily depression) symptoms associated with dementia (BPSD). There is a growing consensus that these behavioral and depressive symptoms, which often accompany dementia, are the most significant problems observed in nursing home residents (Snowden, Sato, & Roy-Byrne, 2003; Sutor, 2002).

In reviewing the hundreds of studies on behavioral and depressive symptoms in dementia, there have been many theoretical, descriptive, exploratory, correlational, and observational studies reported in the professional literature. There have been fewer classic experimental studies with random assignment of subjects to control or usual care conditions. The literature review carried out for this dissertation used the selection criteria listed below to guide inclusion or exclusion of articles.
1. Randomized control trials and quasi-experimental research studies were included in the review.

2. Studies based in nursing homes were included in the review.

3. Elderly (65 years and older) study populations with Alzheimer’s disease, dementia, or cognitive impairment were included in the review.

4. Community-based studies were excluded from the review.

5. Theoretical, descriptive, exploratory, correlational, and observational studies were excluded from the review.

6. Dissertation studies and non-refereed articles were excluded from the review.

7. Studies that were not available in English were excluded from the review.

8. Studies published prior to 1996 were excluded from the review.

It should also be noted that this review did not include pharmacological studies except for the first section on interventions that address medical/physical problems. The focus for this first section is on studies related to pain because pain is one of the most common physical/medical problems referenced in studies on dementia, and it is almost always treated with analgesics. Pain was also one of the most common physical problems observed in the AICT study.

In the literature review that follows, intervention studies involving nursing home residents with dementia will be identified and described briefly. As noted in the preceding paragraph, this review will focus on non-pharmacological interventions except for the first section on physical/medical problems. All of these studies have been carried out within the past twelve years, and each study has been categorized in to one of the
following six categories; 1) medical/physical, (2) psychological, (3) psychosocial, (4) behavioral, (5) meaningful activities, and (6) familial.

In addition to these six subject areas, the literature on interdisciplinary teams will be reviewed as an area of interest in advancing our understanding of how to improve the well-being of nursing home residents with dementia. The section on interdisciplinary teams will be the concluding section in this chapter.

2.5 Interventions that address medical/physical problems

Nursing home residents with dementia almost always have co-occurring physical problems that require ongoing treatment and care. For example, in a recent study of three Maryland nursing homes, it was reported that common problem areas in residents included skin (95%), nutrition/hydration (85%), gastrointestinal (81%), and infections (80%) (Black et al, 2006). It was also noted that these problems are often accompanied by pain and, given the communication difficulties that individuals with dementia experience, adequate management of this pain is a challenge facing all nursing homes (also see Nygaard & Jarland, 2005; Cohen-Mansfield & Lipson, 2002). In fact it is estimated that 45-83% of nursing home residents regularly experience pain (Chu, Schnelle, Cadogan, & Simmons, 2004).

The prevalence of pain in this target population was, not surprisingly, also observed in the residents participating in the AICT study. The problems identified as medical/physical by the AICT almost always addressed pain management rather than an accompanying medical condition. The residents’ medical conditions were addressed as part of their usual care in the nursing home, and utilized treatment protocols and standardized practices for each medical condition. Therefore, this brief review will focus
on pain, rather than specific medical conditions, as one of the most common problems observed in the AICT study.

In carrying out this literature review, it was learned that there are hundreds of articles on pain but very few studies that empirically evaluated approaches to managing pain in nursing home residents with dementia. A search of several electronic data bases using the key terms “pain”, “dementia”, and “nursing homes” revealed that many articles meeting the search criteria have been published over the past 20 years. The Medline data base produced 99 matches dating to 1985. The Psyc Info and Psyc Articles data bases produced 42 and 37 matches, respectively, dating to 1990 and 1987. Social Work Abstracts identified 69 matches when the single search term “pain” was used, but just 2 matches were found when the three search terms (pain, dementia, nursing homes) were used. A query of the CINAHL (nursing) data base found 48 articles fitting the search terms. Although additional articles (i.e. articles not cataloged in the other data bases) were identified, none were randomized control trials of pain management interventions. Using alternative key terms such as “acetaminophen”, “lortab”, and “opioid” in these searches produced few matches and no pertinent studies beyond those already identified in the other data bases.

In addition to this data base search, a search of the journals Pain and Journal of Pain and Symptom Management using the key terms ‘dementia’ and ‘nursing homes’ produced 4 and 7 matches, respectively, dating to 1996 and 1995. There were no intervention studies referenced in any of these articles. The articles that follow are the most empirically sound studies of managing pain in nursing home residents with dementia that were identified in this search of the literature.
examined the effectiveness of low dose opioid therapy in reducing pain and agitation in 25 residents with advanced dementia (MMSE<21) living in a New York City nursing home. This was a double blind trial (without randomization) in which participants received placebo for 4 weeks and, after a one-day interval, received a long-acting opioid (oxycodone 10 mg/12 hours, or morphine 20 mg/day for participants who could not swallow a pill). The primary outcome measure (agitation) was the CMAI. At the end of the trial, there were no significant differences in agitation between the placebo and treatment phases for residents less than 85 years old. However, for the 13 residents over the age of 85, the agitation level at the end of the opioid treatment phase was significantly (p<.05) lower than at the end of the placebo phase.

Baier et al (2004) evaluated a multifaceted intervention to improve the management of pain in 17 Rhode Island nursing homes over a 15 month period. This was a quasi-experimental design with pretest/posttest measures of the prevalence of pain indicator on the quarterly Minimum Data Set (MDS). The MDS is used by the Centers for Medicaid and Medicare Services National Nursing Home Quality Initiative to monitor and improve care. The intervention at each of the participating nursing homes was the formation of a quality improvement team to focus on pain management. The teams’ approach emphasized education on pain management, audit and feedback, Plan-Do-Study-Act quality improvement cycles, one-on-one mentoring at each home, and collaboration among all of the participating facilities. At the end of the 15 month intervention period, the collaborative quality improvement model significantly reduced
the proportion of residents with pain by 41% and improved adherence to clinical care guidelines for nursing homes residents.

Buffum, Sands, Miaskowski, Brod, and Washburn (2004) evaluated the effectiveness of regularly scheduled administration of acetaminophen (650 mg, four times/day) versus as needed (prn) administration of acetaminophen in residents (n=39) with severe dementia (documented in medical records and Global Deterioration Scale score > 4) and a painful condition. This study was carried out at three San Francisco Bay area nursing homes. This was a double-blind, double-dummy, placebo-controlled, crossover trial in which participants randomized to treatment received the four doses of acetaminophen with placebo prn for two weeks and then crossed over to placebo-control for two weeks. The residents randomized to placebo-control received placebo four times daily with acetaminophen prn (not to exceed 2,600 mg/day) for two weeks and then crossed over to treatment. Discomfort was measured on the Discomfort Scale-Dementia of the Alzheimer’s Type (DS-DAT), a nine-item instrument that measures frequency, intensity, and duration of discomfort. At the end of this one month study, no differences were found in the DS-DAT scores of the treatment and placebo-control residents. The authors suggest that a 2,600 mg/day dose of acetaminophen is inadequate for this population especially when there is concurrent degenerative joint disease, fractures, and/or back pain.

Chibnall, Tait, Harman, and Luebbert (2005) evaluated the effectiveness of acetaminophen on behavior, well-being, and psychotropic medication use in nursing home residents (n=25) with moderate to severe dementia. This was a randomized, double-blind, placebo controlled, crossover research design in which residents received
four weeks of acetaminophen (3,000 mg/day) and four weeks of placebo. Outcome measures included Dementia Care Mapping (time spent in behaviors across 26 domains, and the emotional state observed with each behavior) and the Cohen-Mansfield Agitation Inventory. The residents receiving acetaminophen spent more time in social interaction, more time engaged in work-like activity, and less time in their rooms compared to when they received placebo. There were no differences between treatment and control conditions in respect to agitation, emotional well-being, or in the use of psychotropic medication.

Kovach et al (2006) evaluated the effectiveness of a Serial Trial Intervention (STI) to reduce discomfort and behavioral symptoms in residents (n=114) with dementia (MMSE< 23) living in 14 nursing homes. All of the participating homes (8 urban; 6 suburban) were located in a mid-western state, and each home was randomly assigned to the treatment or control arm of the study. The STI uses nonpharmacological treatments and analgesic therapy in a flexible approach that can be customized to the individual resident’s need. Outcome measures for this study included the DS-DAT (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992) and BEHAVE-AD (Reisberg, Ferris, & Franssen, 1985). The intervention period for each resident lasted about 4 weeks and, at the end of the study, the treatment group had significantly (p<.001) more pharmacological treatments (26 vs. 2) and significantly (.001) less discomfort than the control group. There was not a significant difference between treatment and control groups on behavior scores at posttest, nor was there a significant difference in the number of treatment/control residents who received nonpharmacological comfort measures.
Cipher, Clifford, and Roper (2007) investigated the effectiveness of Geropsychological treatment in improving pain, depression, and behavior of nursing home residents (n=44) with mild to moderate dementia (Neurobehavioral Cognitive Status Exam: Kiernan, Mueller, Langston, & Van Dyke, 1987). This was a quasi-experimental study involving consecutive admissions at three nursing facilities in the Dallas, Texas area. Participants in this study received a psychological evaluation, 8 sessions of Multimodal Cognitive-Behavioral Therapy (MCBT), and follow-up psychological evaluation over a 5 week intervention period. The MCBT intervention used a one-on-one approach with residents “to establish a warm emotional relationship” and, when appropriate, involved nursing home staff and family members to collaborate on “individualized treatment plans” (p.30). Numerous outcome measures were used including The Geriatric Multidimensional Pain and Illness Inventory (Clifford, Cipher, & Roper, 2005a), Geriatric Depression Scale (Yesavage, Brink, & Rose, 1983), and Geriatric Level of Dysfunction Scale (Clifford, Cipher, & Roper, 2005b). This last scale is a 19 item behavioral assessment instrument. At the end of the 5 week intervention period, participants demonstrated significant reductions in pain, depression, and emotional distress due to pain. Significant reductions in the intensity, frequency, and duration of behavioral disturbances were also observed although there was no decrease in the types of behavior exhibited by residents following treatment.

In reviewing these articles, there are many strengths and weaknesses that are worth noting. The Manfredi et al. (2003) research was a double-blind study without randomization (quasi-experimental, time-series design) that observed reduced agitation through low-dose opioid therapy but only in the oldest (85+) residents. An assumption
underlying this research was that unrecognized pain could contribute to agitation in nursing home residents, and that opioids may have a direct impact on agitated behavior and/or an analgesic action that decreases agitated behaviors. There are numerous pain assessment measures that have been developed in recent decades and, in view of this, it is unfortunate that the researchers did not use one of these measures to shed more light on how opioids act on pain as well as behavior.

The absence of a pain measure was also evident in the Chibnall et al. (2005) evaluation of acetaminophen. In this randomized control trial, Dementia Care Mapping and the CMAI were used to assess and monitor behavior as “alternative approaches to pain assessment” (Chibnall et al., p.1921). Two positive findings were that residents who received acetaminophen (3,000 mg/day) spent less time in their rooms and were more social than residents in the control condition. No differences between groups were noted in respect to agitation, well-being, or psychotropic medication prescribing. This is an important finding but, again, a pain measure would have provided valuable information and perspective on the alleviation of pain and how this affects behavior.

Buffum et al. (2004) also used a randomized control trial to evaluate the effectiveness of acetaminophen (2,600 mg/day) in managing discomfort in residents with dementia. This study did use a pain measure but no behavioral or agitation measures, and found no differences between treatment and control groups in the mitigation of discomfort. However, it was suggested that 2,600 mg/day was “inadequate for elderly nursing home patients” (Buffum et al., p.1093) with dementia especially if there were concurrent chronic pain problems. In comparing this finding with Chibnall et al., one
might infer that dosing at 3,000 mg/day has a greater therapeutic benefit than dosing at 2,600 mg/day.

The Baier et al. (2004), Kovach et al. (2006), and Cipher et al. (2007) studies all used pain measures to investigate the effectiveness of Quality Improvement Teams, Serial Trial Interventions, and Geropsychological treatment to manage pain/discomfort in nursing home residents with dementia. Baier et al. and Cipher et al. used quasi-experimental research designs with a prevalence of pain indicator from the MDS (Baier et al.) and Geriatric Multidimensional Pain and Illness Inventory (Cipher et al.). Both of these studies observed significant reductions in pain in their study populations, but the lack of randomization and control groups weakens their findings. In addition to this, the reliability of their pain measures is uncertain as the prevalence of pain indicator was chosen as a convenient, readily accessible source of data (Baier et al.). Similarly, the Geriatric Multidimensional Pain and Illness Inventory was recently (2005) developed by the authors of the Geropsychological study (Cipher et al.) and, therefore, the reliability of this instrument has not been established.

Kovach et al used a pain measure (DS-DAT) that has been used by other researchers (e.g. Buffum et al.). The DS-DAT has also been evaluated independently. Stolee et al. (2005) evaluated 39 instruments for assessing pain and the DS-DAT instrument was one of just a few measures that had acceptable validity and reliability. The prevalence of pain indicator from the MDS (Baier et al) and the Geriatric Multidimensional Pain and Illness Inventory (Cipher et al) were not reviewed in the Stolee et al article.
In closing out this section on interventions that address physical/medical problems, it is evident that most of the articles inventoried in the databases that were searched focused on the assessment, measurement, perception, and prevalence of pain. There have been very few studies that empirically evaluate interventions to reduce pain in nursing home residents with dementia. This appraisal is echoed by other researchers who have observed that although there have been many diverse studies on pain, relatively few of them have focused on older individuals with dementia (Horgas & Elliot, 2004).

2.6 Interventions that address psychological problems

Intervention studies that address psychological problems (primarily depression) in nursing home residents with dementia invariably address other issues such as agitation, anxiety, and pain. There have been many correlational and descriptive studies that have shown a statistically significant association between depressive symptoms and disruptive vocalizations (Dwyer & Byrne, 2000), physical or verbal aggression (Menon et al, 2001), and pain (Bartels et al, 2003). This association or clustering of psychological and other symptoms is evident in the phrase “Behavioral and Psychological Symptoms of Dementia” (BPSD) which is commonly seen in the dementia research literature (see, for example, Burgio & Fisher, 2000; Sutor et al, 2003; Turner, 2005).

The studies reviewed in this section examine the effectiveness of non-pharmacological interventions in reducing depressive or cognitive symptoms in residents with dementia. In the literature, numerous articles report on the use of antipsychotic and antidepressant medications to treat BPSE (see Bharani & Snowden, 2005 for a review of evidence-based pharmacological and non-pharmacological interventions) and, recently, even a case study on the use of electroconvulsive therapy (ECT) in a 92 year old woman.
with dementia and psychosis (Katagai, Yasui-Furukori, Kikuchi, & Kaneko, 2007). Although ECT is not a pharmacological intervention, its direct impact on brain functioning parallels the way psychoactive medications act on the brain.

This review will focus on non-pharmacological interventions because these types of interventions were the primary focus of the AICT. Pharmacological treatments were often discussed during AICT meetings because many of the residents in the AICT study had psychological problems such as depression. However, pharmacological treatment of depression almost always prescribed selective serotonin reuptake inhibiting (SSRI) medication following a standard treatment protocol. The AICT would occasionally advocate for pharmacological treatment of depressed residents but the decision to treat with antidepressants was always made by the primary physician. As a result, the focus of the AICT was on non-pharmacological treatment of psychological problems.

In carrying out this literature review of interventions that address psychological problems of nursing home residents with dementia, the search terms of “depression”, “dementia”, and “nursing homes” were used. The Medline data base produced 237 matches dating to 1985. An initial query of the Psyc Info data base produced 1,135 matches dating to 1982. Given the large number of matches, the scope of the search in Psyc Info was narrowed to search terms in the ‘abstracts’ of articles rather than ‘anywhere’ in the text. This adjustment returned 80 matches dating to 1982. The Psyc Articles data base returned 0 matches when limited to the abstracts but increased to 130 with no limitations applied to the search. The CINAHL data base produced 103 matches dating to 1990 in a search using the terms “depression”, “dementia”, and “nursing homes”. Social Work Abstracts identified 69 matches when the single search term
“depression” was used, but just 2 matches were found when the three search terms (depression, dementia, nursing homes) were used.

In the review of the articles that follow, many of the studies address agitation, behavior, and/or pain in addition to depression. A study on bright light treatment (Lyketsos, Veiel, Baker, & Steele, 1999) examined nocturnal sleep, depression, and agitation. Two of the studies focused on how depression and behavior were affected by staff training and education (Proctor et al, 1999) and pleasurable activities (Lichtenberg, Kemp-Havican, MacNeill, & Johnson, 2005) interventions. Several of the studies investigated the effectiveness of activity/exercise interventions in reducing depression along with a variety of other symptoms often observed in nursing home residents with dementia. All of the studies, except one (Stevens & Killeen, 2006) addressed depression or mood in their outcome measures.

Lyketsos, Veiel, Baker, and Steele (1999) examined the effect of bright light therapy on agitation and depression in residents (n=15) of Copper Ridge, a Maryland chronic care residence for individuals with dementia (DSM-IV criteria). Residents were randomized to bright light or control conditions for 4 weeks and, after a week of no treatment, crossed over to the other condition. The control condition was identical to the treatment condition except that a dim, low frequency light was substituted for the full spectrum bright light in the lamp fixture. Outcome measures included a sleep log, the Behave-AD (Reisberg et al, 1987) and Cornell Scale for Depression in Dementia. Residents receiving bright light therapy experienced a statistically significant (p<.05) increase in nocturnal sleep whereas the residents in the control condition did not
experience a significant increase in their nocturnal sleep. There were no differences between groups on the depression or on the agitated behavior measures.

Proctor et al (1999) evaluated an intervention consisting of staff training and education in psychosocial management of depression and behavior problems of residents (n=120) living in 12 matched nursing and residential homes in the UK. The 12 homes were randomized to intervention or control conditions. The staff working in the intervention homes received seven 1-hour training and education sessions from members of a hospital outreach team, and weekly visits with an experienced psychiatric nurse who provided guidance in the development of care planning skills. The AGECAT (Automatic Geriatric Examination for Computer-Assisted Taxonomy; Copeland, Dewey, & Griffiths-Jones, 1986) outcome measure was used to assess cognitive and depressive symptoms. The Crichton Royal behavioural rating scale and Barthel ADL index (Wade & Collin, 1988) were used to measure behavioral characteristics and ability to perform activities of daily living. At the end of the 6-month intervention, residents in the treatment condition had significant improvement in their depression and cognitive impairment scores, but there was no difference between groups in respect to scores on behavior and ADL rating scales.

Fitzsimmons (2001) tested the effectiveness of a wheelchair biking program in treating depressive symptoms in the residents (n=39) of a veteran’s home in upstate New York. Residents were randomized to treatment or control conditions, and treatment was scheduled for 1 hour per day, 5 days per week over a period of 2 weeks. Each treatment session lasted an hour with 15 minutes wheelchair biking and the remainder of the session devoted to a small group discussion of each resident’s wheelchair biking
experience. The short-form Geriatric Depression Scale (Sheikh & Yesavage, 1986) was administered at pretest and at posttest. The residents in the wheelchair biking program achieved a statistically significant reduction in depression scores. The depression scores of the control group actually increased (in contrast with the treatment group) although the increase was not statistically significant. Over half (56%) of the participating residents in this study had a diagnosis of dementia, and this subgroup experienced the greatest benefit from this intervention.

Heyn (2003) evaluated a multisensory exercise program for nursing home residents (n=13) with dementia (MMSE<22). The multisensory exercise program engaged residents in a focused attention and warm-up session (seated exercise with soft music, storytelling, and mental imagery) followed by aerobic and flexibility exercises and strength training. Each session concluded with guided instructions on relaxation and breathing techniques. These activities were done in a group that met three times a week for a period of eight weeks. This was a quasi-experimental research design utilizing a convenience sample and single treatment group without randomization or comparison groups. Outcome measures included a Caregiver Mood Report (new instrument being developed by author), Menorah Park Engagement Scale (Camp, Foss, O’Hanlon, & Stevens, 1995), and several physiological indicators (heart rate, blood pressure, and weight). Following the multisensory exercise intervention, 61.5% of the residents showed an overall improvement in mood and 69.2% engaged in more than half of the activities. A significant improvement in the average resting heart rate was observed at the end of the study but there were no significant differences in blood pressure or weight.
Lichtenberg, Kemp-Havican, MacNeill, and Johnson (2005) compared a pleasurable activities/behavioral treatment with usual care in reducing depression and behavioral disturbances in residents (n=20) of two specialized dementia care units in a Michigan nursing home. This pilot study randomized one unit to provide the treatment intervention and the other unit to provide usual care for their respective residents. The intervention consisted of training nursing assistants in behavioral treatment and management of dementia. Concurrently with this training, the nursing assistants were guided in how to engage residents in a one-to-one session of pleasurable activities for 20-30 minutes, three times a week. The pleasurable activities were individualized for each resident and the intervention continued for three months. Outcome measures included The Behave-AD, the Geriatric Depression Scale, and the Cornell Scale for Depression in Dementia. The treatment group had significantly less troublesome or dangerous behavior following the intervention when compared to the usual care group. Both groups experienced significant reductions in the frequency of behavioral disturbances at the end of 3 months. There was not a significant reduction in depression scores over time for either group.

Lyne et al (2006) evaluated the effectiveness of an individualized care planning intervention to reduce depression in residents (n=114) with moderate to mild dementia (MMSE>9) living in 14 British residential care homes. Staffs at the homes were offered mental health training to improve their ability to detect depression in the residents and to carry out a care planning intervention to alleviate depression in the residents who were symptomatic. This was a quasi-experimental research design that used a convenience sample of homes and residents. The study also used a non-equivalent (residents without
depression) comparison group (n=168). The primary outcome measure was the Depression Scale of the Geriatric Mental State Schedule (GMS-DS: Ravindran, Welburn, & Copeland, 1994), a 33 item scale with a scoring range from 0 (no depression) to 71. Following the 8 week care planning intervention, there was a significant (p<.001) reduction in the GMS-DS scores for the intervention group. It is worth noting that in a subsidiary analysis it was found that the intervention was less effective in reducing depression scores in the residents with more severe dementia (MMSE<21).

Stevens and Killeen (2006) tested the impact of exercise on the cognitive symptoms of residents (n=75) with dementia living at an Australian nursing home. Residents were randomized to a treatment, placebo, or control group for the 12-week intervention period. The treatment group participated in an exercise group (designed for frail, aged populations) that met three times per week, with each session lasting 30 minutes. The placebo group received a social visit equivalent (in frequency and duration) to the treatment group. The control group received usual care i.e. no intervention. Outcome measures included the Clock-Drawing test (Shulman et al., 1993) to measure the progression of cognitive symptoms, and the Revised Elderly Persons Disabilities Scale (Fleming & Bowles, 1993) to measure the level of disability. At the end of the 12-week intervention period, the exercise group had significantly less cognitive decline and disability in their activities of daily living compared to the placebo and control conditions. In addition to this, the exercise group actually showed some reversal in their disability scores following the period of treatment.

Rolland et al, 2007 evaluated the effectiveness of an exercise program in improving the ability of nursing home residents (n=134) to perform ADLs while
decreasing depression and behavioral disturbances. The residents were recruited from five nursing homes in Toulouse, France and all residents were diagnosed with Alzheimer’s disease or had a MMSE score of less than 25. Residents were randomly assigned to a small (2-7 participants) exercise group (treatment) or usual care (control). The treatment group met twice a week for one hour and, during this hour, received walk, strength, balance, and flexibility training. The intervention period was 12 months long. Outcome measures included the Katz Index of ADLs (Katz et al, 1963), the Montgomery-Asberg Depression Rating Scale (Muller-Thomsen et al, 2005), and the Neuropsychiatric Inventory (Holmes et al, 2004), and the Mini-Nutritional Assessment (Velas et al, 1999). At the end of the intervention period, the exercise group showed a significantly slower decline in ADL scores compared to the usual care group. There was not a significant difference between groups on depression, behavioral disturbance, or nutritional status scores.

These studies provide some support for the value of exercise, staff training and education, and individualized care planning in addressing psychological problems in nursing home residents with dementia. Psychological problems in this population include depression and/or cognitive decline which is often reflected in decreasing activities of daily living. Exercise interventions have been effective in slowing cognitive decline and even increasing activities of daily living (Stevens & Killeen, 2006; Rolland et al, 2007). In a similar vein, another researcher (Heyn) observed an improvement in residents’ engagement in physical activity and an improvement in mood following participation in a multisensory exercise program. It should be noted, however, that the Heyn study was a
quasi-experimental design without randomization and without a control or comparison group.

In respect to the psychological problem of depression, the staff training and education (Proctor et al, 1999) and individualized care planning (Lyne et al, 2006) interventions observed an improvement in the depression scores of residents in the treatment groups compared to the control groups although the Lyne et al study was a quasi-experimental design without randomization or a genuine control group. Lyne et al also observed that the care planning intervention was less effective in reducing the depression of more severely demented residents. The recreational wheelchair biking program (Fitzsimmons, 2001) also found a significant improvement in the depression scores of individuals who participated in this activity. Unlike the Lyne et al study, Fitzsimmons found that the residents with dementia benefitted more from the intervention than the participants without a dementia diagnosis. The individualized pleasurable activities intervention (Lichtenburg et al, 2005) and bright light treatment (Lyketsos et al, 1999) did not produce a significant reduction in depression. Lichtenburg et al did observe a reduction in the severity of behavioral disturbances in the pleasurable activities group compared to usual care.

There are other non-pharmacological interventions described in the literature that target depression in nursing home residents but many of these studies exclude residents with dementia. For example, in one placebo-controlled crossover study, bright light treatment significantly reduced depression in nursing home residents (n=10) (Sumaya, Rienzi, Deegan, & Moss, 2001). In another randomized controlled trial, individualized treatment of depressed residents (n=85) utilizing a geropsychiatric nurse and trained
volunteers significantly reduced depression in the individuals assigned to the treatment condition (McCurren, Dowe, Rattle, & Looney, 1999). These studies were not included in the above review because residents with dementia did not meet the eligibility criteria for participation in either study.

2.7 Interventions that address psychosocial problems

Interventions that address psychosocial problems focus on the psychological and social elements that contribute to behavior, mood, and level of functioning. These interventions are often characterized as ‘person-centered’ and can take the form of individual and group therapies, social-recreational activities, skills training, and support groups. For nursing home residents with dementia, there are several treatment approaches reported on in the literature that are person-centered and address psychosocial needs. These approaches are known as emotion-oriented care, and they are designed to supplement the traditional medical model of care that is used in most nursing homes (Finnema et al, 2005). Emotion-oriented care, which also includes validation therapy and reminiscence therapy, strives to improve the emotional, social, and adaptive functioning of the resident and, ultimately, improve their quality of life. Although these are not the only interventions used to address psychosocial problems in nursing home residents with dementia, the interventions reported on in this section are the most empirically-sound studies appearing in the literature.

In carrying out this literature review of interventions that address psychosocial problems of nursing home residents with dementia, the search terms of “psychosocial”, “dementia”, and “nursing homes” were used. The Medline data base produced 49 matches dating to 1976. The first search of the Psyc Info data base produced 619
matches dating to 1980. Given the large number of matches, the scope of the search in Psyc Info was narrowed to search terms in the ‘abstracts’ of articles rather than ‘anywhere’ in the text. This adjustment returned 14 matches dating to 1988. The Psyc Articles database returned 50 matches dating to 1987 when the three search terms were applied to ‘anywhere’ in the text while the CINAHL database produced 186 matches dating to 1989 using the same approach. Social Work Abstracts found no matches using the three search terms but unearthed 16 matches when the two search terms “psychosocial” and “dementia” were used.

Toseland et al (1997) compared the effectiveness of validation therapy, social contact, and usual care conditions in nursing home residents (n=88) with moderate to severe dementia (Short Portable Mental Status Questionnaire & Validation Screening Instrument). This was a single-blind, placebo-controlled study in which residents at 4 participating nursing homes were randomly assigned to one of the 3 groups (validation therapy, social contact, or usual care). The usual care group participated in the usual social and recreational activities offered at each home but they did not meet as a group. The validation and social contact groups (6-9 residents/group) met for 30 minutes, 4 times a week for 52 weeks. Validation therapy is a person-centered approach to care that empathically supports the experience and communication of the demented individual. This reportedly has a calming effect on the resident, promotes interaction, and reduces agitated, aggressive, and withdrawn behavior. Outcome measures included the Multidimensional Observation Scale for Elderly Subject (MOSES; Pruchno, Kleban, & Resch, 1988), the Cohen-Mansfield Agitation Inventory, and the Geriatric Indices of Positive Behavior, a 23 item instrument developed for this study. In this study, validation
therapy was found to be more effective than social contact (placebo) and usual care in reducing problem behaviors but it had no impact on the use of psychotropic medications, physical restraints, or the amount of time nursing staff devoted to managing challenging resident behaviors.

Spector, Orrell, Davies, and Woods (2001) examined the impact of a reality orientation/cognition-based therapeutic approach for elderly demented (DSM IV) individuals (n=27) living in long-term residential homes or attending a geriatric day center in the U.K. The intervention consisted of twice weekly group sessions of 45 minutes duration convening for a total of 15 sessions. Reality orientation (naming people, objects, and dates), reminiscence therapy (reviewing significant life events), and multisensory stimulation (theme song, scented candle, tea and biscuits) were used in welcoming and engaging participants in the group intervention. This was a randomized control pilot study in which the participants assigned to the control condition received usual care. Outcome measures included the Mini-Mental State Exam (MMSE), Cornell Scale for Depression in Dementia (CSDD), and Rating Anxiety in Dementia (RAID; Shankar, Walker, Frost, & Orrell, 1999). Following the period of intervention, participants in the treatment group experienced a significant (p=.02) improvement in their depression scores compared to the control group. The treatment group also experienced improvement in their cognition (MMSE) and anxiety (RAID) scores while the control group showed no change in cognition and an increase in anxiety. These differences, although noteworthy, did not achieve statistical significance.

Schrijnemaekers et al (2002) investigated the effectiveness of emotion-oriented care for residents (n=151) with cognitive impairment (MMSE< 21) and behavior
problems living in 16 homes for the elderly. In the Netherlands (the setting for this study), homes for the elderly are similar to nursing homes in providing care for individuals with physical and mental impairments. The intervention, emotion-oriented care, uses elements from validation therapy (respecting and accepting the disoriented individual’s perspective) and adds elements of reminiscence and sensory stimulating approaches in communicating with demented elderly. Eight of the homes were randomized to the treatment condition and 8 were randomized to the control condition (usual care). The intervention was carried out over 8 months with behavioral outcome measures taken at baseline, 3, 6, and 12 months. The primary outcome measure was the Dutch Behavior Observation Scale for Psycho-geriatric Inpatients (Verstraten & van Eekelen, 1987), an 82 item instrument with 14 sub-scales that measure a range of behaviors. No statistically significant difference was observed between the treatment and control groups on any of the behavioral measures.

Lai, Chi, and Kayser-Jones (2003) examined the effectiveness of a specific reminiscence approach to promote the well-being of nursing home residents (n=101) with dementia (DSM IV). This was a single-blind, comparison group study that recruited residents from 2 publicly funded nursing homes in China, and randomized participants to intervention, comparison, and control conditions. The intervention and comparison groups met for 30 minutes, once a week for 6 weeks, while the control group received no intervention. The intervention was a specific reminiscence approach that was individualized to the memorable life events and unique life experiences of the particular resident. The comparison group provided friendly discussions to control for the social contact and attention required by the intervention, and the control group received the
usual care provided by the homes. The outcome measures used in this study were the Social Engagement Scale (Schroll et al, 1997) and the Well-being/Ill-being Scale (Brooker & Duce, 2000). There were no significant differences between the 3 groups over time, although there was significant improvement in the reminiscence group’s psychosocial well-being scores at the end of the 6 week intervention.

Spector et al (2003) evaluated the effectiveness of cognitive stimulation therapy (CST) in improving the quality of life and cognitive functioning of older people (n=167) with dementia (DSM IV; MMSE 10 – 24). This study was carried out in the U.K. with participants drawn from 18 residential homes (nursing homes) and 5 day centres randomly assigned to CST or control (usual care) conditions. The CST intervention was scheduled twice a week over a 7 week period for a total of 14 sessions. Sessions included reality orientation and cognitive stimulation activities that “encouraged the use of information processing rather than factual knowledge” (p. 249). Outcome measures included the MMSE, Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog; Rosen, Mohs, & Davis, 1984), Quality of Life – Alzheimer’s Disease scale (QoL-AD; Logsdon et al, 1999), and Cornell Scale for Depression in Dementia (CSDD). Following treatment, the intervention group had improved significantly compared to the control group on the cognitive (MMSE, p=.04 & ADAS, p=.01) and quality of life (QoL-AD, p=.03) measures. There was no difference between groups in respect to measures of depression and behavior.

Politis et al (2004) compared the effectiveness of a reminiscence-based activity therapy with a control of unstructured time and attention at a model facility (Maryland) specializing in the long term care of individuals (n=36) with dementia (DSM IV; Global
Deterioration Scale score: 3 – 5). In addition to their cognitive impairment, residents in this study were suffering from apathy with little interest in day-to-day activities. The treatment and control conditions were carried out in 30-minute, one-on-one sessions with an activity therapist, 3 times a week over a period of 4 weeks. The reminiscence-based intervention utilized a standardized geriatrics network kit with a choice of five activities to be chosen by the participant. The control condition involved a discussion of the participant’s interests and an opportunity to participate in an activity. Outcome measures included the Neuropsychiatry Inventory (NPI: Cummings et al, 1994) and the Alzheimer’s Disease Related Quality of Life (ADQRL: Rabins et al, 1999). There was a significant reduction in apathy scores (NPI subsection) in both conditions but the reminiscence-based intervention was not more effective than unstructured time and attention. In fact, the residents in the time and attention control achieved significantly improved scores (within group) on the ADQRL while the residents in treatment experienced just a slight improvement in their scores.

Finnema et al (2005) evaluated the effect of integrated emotion-oriented care on residents (n=146) of 14 Dutch nursing homes. This was a 9 month multi-site study in which matched wards were randomized to treatment or control conditions. To avoid contamination between treatment and control wards, nursing homes were designated as control or treatment facilities exclusively. In this study, emotion-oriented care involved the use of empathic skills to try to understand what the resident was experiencing in the context of their life history while acknowledging their past and present experiences. Staff on the treatment wards received ongoing training in emotion-oriented care including how to organize and lead an emotion-oriented group for residents. Numerous outcome
measures of behavior and mood including the Cohen-Mansfield Agitation Inventory (CMAI), Cornell Scale for Depression in Dementia (CSDD), Dutch Behavior Observation Scale for Psychogeriatric In-patients (Verstraten & van Eekelen, 1987), and Philadelphia Geriatric Center Morale Scale (Lawton, 1975) were used to operationalize the Adaptation-coping model central to this research project. At the end of this 9 month study, it was found that treatment group residents with mild to moderate dementia (Global Deterioration Scale score: 1 – 4) scored significantly better on the adaptive tasks of preserving a positive self image and maintaining an emotional balance compared to the control group residents with mild to moderate dementia. For the more severely demented residents (Global Deterioration Scale score: 5 – 6), there was no difference between emotional-oriented care and usual care on any of the outcome measures.

Teri et al (2005) tested the impact of a dementia-specific Staff Training in Assisted living Residences (STAR) intervention on residents (n=31) with a diagnosis of Alzheimer’s disease or related dementia (mean MMSE=16). Residents in the STAR homes received care that was guided by a model of person-environment fit in which the values of dignity and respect for the residents were emphasized. This model of care also focused on staff responsiveness to resident needs and the improvement of staff skills to enhance the care provided to residents. To evaluate the effectiveness of the STAR intervention, four standardized measures of depression, anxiety, and behavior were administered at baseline and posttest (8 weeks). The 4 homes participating in the study were randomly assigned to treatment (STAR) or control (usual care) conditions. Outcome measures included the Geriatric Depression Scale, Clinical Anxiety Scale (Fischer & Corcoran, 1994), Revised Memory and Behavior Problem Checklist (Teri et
al, 1992), Agitated Behaviors in Dementia (Logsdon et al, 1999), and Neuropsychiatric Inventory (Cummings et al, 1994). Following the 8 week intervention period, the residents in the STAR homes experienced significantly reduced levels of affective and behavioral distress compared to residents in homes receiving usual care. In addition to this, residents in the control condition worsened during the intervention period while the STAR residents improved.

van Weert et al (2005) investigated the effectiveness of snoezelen in ameliorating the behavioral and mood problems of residents (n=125) with dementia (DSM diagnosis) in six Dutch nursing homes. Snoezelen is a person-centered approach to dementia care that “actively stimulates the senses using light, sound, smell, and taste.” (p.24). In this quasiexperimental study, each of the 6 participating nursing homes designated an experimental and control ward among their psychogeriatric wards, with measures of agitation (CMAI), behavior (Dutch Behavior Observation Scale for Psychogeriatric In-patients, Verstraten & van Eekelen,1987) and depression (CSDD) administered at pre-test and at posttest immediately following the 18-month intervention. The residents receiving snoezelen care achieved significant reductions on measures of apathy, loss of decorum, rebellious behavior, aggressive behavior, and depression compared to the residents who received usual care.

Deponte & Missan (2007) evaluated the effectiveness of validation therapy (VT) and sensorial reminiscence (SR) in residents (n=27) with moderate to severe dementia (MMSE: 2-20) living at a large Italian nursing home. The residents were matched for age and functional status, and then randomly assigned to the VT, SR, or control group. The two experimental groups (VT & SR) met 2 days/week for 3 months. Each treatment
session began at 4:00 in the afternoon and lasted from 45 to 60 minutes. Outcome measures included the MMSE, the Bedford Alzheimer Nursing Severity Scale (BANSS: Volicer, Hurley, Lathi, & Kowall, 1994), and Neuropsychiatric Inventory (NPI). The VT and SR groups both experienced a significant decrease (VT: p<.03; SR: p<.01) in their behavioral problems scores (NPI), and the SR group achieved significant improvement (p<.05) in cognitive functioning (MMSE) and performance (p<.02) of activities of daily living (BANSS). The VT group also improved scores on their MMSE but this change did not reach statistical significance. By contrast, the control group experienced deterioration on their MMSE and NPI outcome measures with a significant decline (p<.05) observed on their BANNS scores. In spite of these noteworthy changes within each of the conditions, there was not a statistically significant difference between groups on the outcome measures.

In this review of interventions that address psychosocial problems, over half of the cited studies examined the affective status (primarily depression but also anxiety) of nursing home residents with dementia. There was some support for reality orientation and reminiscence therapy (Spector et al, 2001), as well as Snoezelen (van Weert et al, 2005), to significantly reduce depression compared to usual care. Teri et al (2005) also observed significant reductions in depression for residents receiving an individualized person-environment approach to care compared to residents receiving the usual care. It should be noted that although participants in this study had Alzheimer’s or a related dementia, it was conducted at assisted living facilities rather than nursing homes.

Two studies were unable to find any improvement in the scores of depression measures following intervention. Spector et al (2003) carried out a large study based on
their pilot referenced in the preceding paragraph (Spector et al, 2001). This larger study failed to find a significant difference between treatment and control groups on depression and behavioral outcome measures. The residents in the treatment condition, however, did achieve significantly improved scores on cognitive and quality of life measures compared to residents in the control condition. Similarly, Finnema et al’s (2005) evaluation of emotion-oriented care observed no difference between treatment and control groups on depression measures following the intervention. A significant difference between groups was observed in respect to the treatment group’s improvement on the adaptive task of preserving a positive self image and on maintaining an emotional balance.

The findings of the studies in this section support the need for further research. All of the studies use a social treatment model that is rooted in an ethical and humane approach to care, and many of these interventions were based on evidence-based practice or earlier studies that seemed to support a particular approach. The findings in respect to depression are mixed, but several of the studies found significant improvement on measures of cognitive functioning following reminiscence and cognitive stimulation interventions (Spector et al, 2001 & 2003; Deponte & Missan, 2002). Another investigation of reminiscence therapy observed a significant improvement on measures of psychosocial well-being (Lai et al, 2003) in both the intervention (life story) group and comparison (topical discussion) group, whereas the control (no intervention) group did not achieve significant change in the outcome measures. This supports the idea that different kinds of social activity are better than none when it comes to enhancing the psychosocial well-being of nursing home residents with dementia.
There were some other unexpected findings in several of the studies covered in this review. The Politis et al (2004) investigation of reminiscence activity therapy and apathy found that the reminiscence intervention and the “time and attention” placebo both achieved significant within group improvement on the apathy measure. In addition to this, the “time and attention” placebo group scored significant increases on their quality of life scores while the treatment group’s improvement did not reach statistical significance. In the Lai et al (2003) study, both the reminiscence treatment group and the “attention and social contact” comparison group experienced significant improvement in their Social Engagement Scale scores. The Deponte and Missan (2007) evaluation of validation therapy also used a comparison group (“sensorial reminiscence”) and found that residents in both conditions (validation therapy and sensorial reminiscence) had significantly fewer behavior problems after the intervention period. The comparison group, however, was the only group to significantly increase their scores on the cognitive functioning measure. These findings suggest that different types of social treatment/interaction can be effective when it comes to improving the well-being of nursing home residents with dementia. Unfortunately, it is not clear what treatment components or elements are most influential in producing these beneficial effects. This demonstrates the need for further research in this area.

2.8 Interventions that address behavior problems

In the field of aging, there is widespread interest in interventions that address behavior problems in the demented elderly. This interest is reflected in the frequent references in the literature to “behavioral and psychological symptoms of dementia” (BPSD) in the aging population. This widespread interest in treating behavioral problems
in this population can be seen in the numerous literature reviews published in professional journals. For example, Bharani and Snowden (2005) reviewed evidence-based interventions for nursing home residents with dementia-related behavioral symptoms. Turner (2005) published a review of non-pharmacological interventions to treat the behavioral symptoms of dementia in residential settings. Still others have reviewed the effects of psychosocial methods on depressed, aggressive, and apathetic behaviors of people with dementia (Verkaik, van Weert, & Francke, 2005) and psychological approaches in managing behavioral and other symptoms of dementia (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). Behavioral symptoms in this population include wandering, striking out at others physically, verbal aggression, repetitive calling out, screaming, and an array of other behaviors that are often labeled as agitation. In the AICT study, agitation and disruptive behaviors were frequently addressed by the team in developing individualized plans of care.

In carrying out this literature review of interventions that address behavioral problems of nursing home residents with dementia, the search terms of “behavior”, “dementia”, and “nursing homes” were used. In most of the electronic databases, these three terms produced matches ranging from 189 (CINAHL) to 1,291 (PsycINFO). In an effort to manage the scope of this review, searches were modified from “anywhere in the text” to a search of the abstracts. Using this strategy, the Medline data base produced 69 matches dating to 1989, and CINAHL produced 37 matches dating to 1987. The PsycINFO data base identified 58 articles dating to 1981 while PsycArticles identified no matches. Opening up the search to “anywhere in the text” in PsycArticles produced 95 matches dating to 1985. This open, unrestricted approach was used in searching Social
Work Abstracts and 8 articles were found dating to 1993. Most of the articles identified in this search were comparative, correlational, or descriptive including surveys. The articles that are summarized in this section are randomized control trials or quasiexperimental research designs.

Alessi et al (1999) carried out a study that combined physical activity and environmental modification to improve sleep and agitation in nursing home residents (n=29). Residents of a community nursing home in Los Angeles were randomized to a treatment or placebo-control condition for a period of 14 weeks. The treatment condition combined increased physical activity during the day (exercise and walking activity) and nighttime nursing care practices designed to reduce noise and sleep disruptions. The placebo-control condition consisted of usual care during the day and the aforementioned nursing care practices at night. Outcome measures included instrumental (wrist actigraphy) and observational monitoring of daytime and nighttime activity, sleep, and agitation. At the end of the intervention period, there was a statistically significant 22% reduction in agitation in the treatment group while agitation in the placebo-control group increased 150%. Nighttime sleep increased significantly (p<.05) for the treatment group compared to the control group, and the treatment group also spent significantly (p<.05) less time in bed than the control group during the day.

McCallion, Toseland, Lacey, and Banks (1999) developed and evaluated a communication skills program for nursing assistants working with moderately to severely demented nursing home residents (n=105). Participating units at two skilled nursing facilities in upstate New York were randomly assigned to treatment or control conditions. The primary outcome measure for evaluating the well-being of the residents was the
Cohen-Mansfield Agitation Inventory (CMAI). The CMAI was administered at baseline, 3 months, and 6 months. The residents receiving care on the units assigned to the treatment arm of the study experienced a statistically significant decline on the subscale measuring verbally agitated behavior. There was not a significant change within or between groups on the CMAI subscales measuring aggressive behaviors and physically nonaggressive behaviors.

Beck et al (2002) evaluated the effect of three behavioral interventions on disruptive behavior in demented (MMSE < 21) nursing home residents (n=127). This study was carried out over a period of 12 weeks at seven nursing homes in Arkansas and Maryland. The participating residents at each home were randomized into one of five groups; 1) an activities of daily living (ADL) group; 2) a psychosocial activity (PS) group; 3) a combination of ADL and PS group (CB); 4) a placebo control group of one-to-one interaction between the resident and the project nursing assistant; and 5) a usual care control group. The interventions were scheduled daily and lasted from 30 (placebo control) to 90 (CB) minutes. The primary behavioral measure was the Disruptive Behavior Scale (DBS: Beck et al, 1997), which closely corresponds to the Cohen-Mansfield Agitation Inventory with its subscales of physically aggressive, physically nonaggressive, and verbally agitated behaviors. Two measures of affect, the Observable Displays of Affect Scale (ODAS: Vogelpohl & Beck, 1997) and the Apparent Affect Rating Scale (AARS: Lawton et al, 1996), were also used as outcome measures. At the end of this study, there was not a reduction in disruptive behavior (DBS) in the treatment groups compared to the control groups. The treatment groups did have significantly more positive facial expressions (p<.001) and positive body posture/movements (p<.001) on
the ODAS, and significantly more contentment (p=.037) and interest (p=.028) on the AARS in comparison to the control groups.

Cott et al (2002) examined the effects of a walking/talking program on communication, ambulation and functional status in residents (n=86) with Alzheimer’s disease (medical diagnosis & MMSE < 20) living at three long-term care facilities in Metropolitan Toronto. Residents were randomly assigned to one of three conditions; 1) a walk-and-talk group; 2) a talk-only group; or 3) no intervention control group. The residents in the treatment conditions carried out their assigned activity in pairs for 30 minutes/day, 5 days/week over a 16 week period. Outcome measures included the Functional Assessment of Communication Skills for Adults (FACS: Frattali et al, 1995), 2 minute walk test (Cooper, 1968), and the London Psychogeriatric Rating Scale (LPRS: Hersch, Kral, & Palmer, 1978) which evaluated mental organization, physical disability, socially irritating behavior, and disengagement. These were administered prior to (pretest) and following (posttest) this 16 week intervention. Following this intervention period, the walk-and-talk group was not able to achieve statistically significant improvement on any of the outcome measures compared to the talk-only group or the control group. All three groups improved significantly (within group) on some of the subscale outcome measures but an additional analysis found that the variability observed in some of these outcome measures was explained by the residents’ level of cognitive impairment rather than the intervention.

Remington (2002) examined the impact of calming music and hand massage on the agitation of nursing home residents (n=68) with dementia (medical records diagnosis). Residents were randomized to one of four conditions; 1) calming music, 2)
hand massage, 3) concurrent calming music and hand massage, or 4) no intervention (control). Treatment in each condition lasted 10 minutes, and agitation was measured just prior to the intervention, during the intervention, immediately following the intervention, and at one hour after the intervention. Agitation was measured with the Cohen-Mansfield Agitation Inventory, and this was the primary outcome measure. All three treatment groups experienced a significant reduction in their agitation scores compared to the control group (no intervention), and this benefit was sustained and increased at one hour following the treatment. Calming music and hand massage were both effective in reducing agitation but no additional benefit was achieved by combining these two interventions.

Ancoli-Israel et al (2003) evaluated the effect of bright light on the agitated behavior of nursing home residents (n=92) with severe Alzheimer’s disease (medical records diagnosis; MMSE < 23). Residents were randomized to one of three conditions; 1) morning bright light, 2) morning dim red light, or 3) evening bright light. Residents were exposed to one of the treatment conditions for 2-hour periods, once a day, on 10 consecutive days. The primary outcome measures were the Cohen-Mansfield Agitation Inventory and the Agitated Behavior Rating Scale (Bliwise & Lee, 1993). These were administered at baseline, days 5 and 10 (posttest) of the intervention, and at 5 days after completion of intervention (follow-up). It was found that morning bright light delayed “the peak of the agitation rhythm” (p. 198) by 1½ hours, while dim red morning light and evening bright light had no affect on agitation or circadian rhythms. Most significantly, none of the treatment conditions reduced agitation scores.
Kovach et al (2004) tested the effectiveness of a BACE (Balancing Arousal Controls Excesses) intervention in reducing agitation in residents (n=78) with moderate or severe dementia (MMSE < 16; Stage 6 or 7 on Functional Assessment Staging Tool, Reisberg, Ferris, & Franssen, 1985) living in 13 long-term care facilities located in the Midwest. This was a pretest-posttest, double-blind research design in which residents were randomized to experimental (BACE) or control conditions. BACE is predicated on the assumption that agitation is linked to an imbalance between stimulating and calming activities. Each resident’s activity level was evaluated and adjusted to achieve a balance of high and low stimulating activities during the 8:00 a.m. to 8:00 p.m. observation period. This resulted in individualized activities schedules for each of the residents during the one week period in which they experienced the treatment condition. The primary outcome measure was agitation. It was measured on a scale of agitation intensity parameters used in conjunction with the 29 behavioral items delineated on the Cohen-Mansfield Agitation Inventory. The residents who received the BACE intervention had a statistically significant (p<.001) reduction in agitation scores from pretest to posttest compared to the residents serving as controls whose agitation scores did not change during the period of intervention.

Sloane et al (2004) evaluated two bathing techniques to reduce agitation, aggression, and discomfort in nursing home residents (n=69) with dementia (medical records diagnosis; Minimum Data Set cognition scores > 4). The study was carried out in fifteen nursing homes (nine in Oregon; six in North Carolina) with five homes randomized to control conditions and ten homes randomized to treatment conditions lasting six weeks. The two treatments were person-centered showering and towel bath.
The person-centered showering uses an approach that focuses more on the person during bathing rather than the tasks involved in bathing. The towel bath is an in-bed method of bathing that, for this study, was also person-centered in attending to each resident’s comfort and preferences during bathing. The primary outcome measures evaluated agitation, aggressive behaviors, and discomfort using the Care Recipient Behavior Assessment, an instrument developed by this study’s research team. This instrument is derived from the Cohen-Mansfield Agitation Inventory which was also used as an outcome measure. Following the period of intervention, agitation, aggression, and discomfort measures all declined significantly in both treatment conditions but not in the control condition. There was not a significant difference between the two techniques (person-centered & towel bath) in respect to reductions in agitation and aggression, but there was less discomfort for residents receiving towel baths.

Woods, Craven, & Whitney (2005) examined the effect of therapeutic touch on the behavioral symptoms of residents (n=57) with dementia (MMSE<20) at three Long Term Care facilities in a western Canadian province. Residents were randomized to one of three conditions; 1) therapeutic touch; 2) placebo therapeutic touch; and 3) usual care. The placebo therapeutic touch mimicked the movements of the experimental condition but there was no attempt to foster “a quiet meditative state, concentrate on the person as whole, or direct a sense of balance” (p. 69) in the resident. The treatment and placebo interventions were administered for 5-7 minutes, twice a day over a three-day period. Outcome measures included the Revised Memory and Behavior Checklist (Teri et al, 1992) and the Modified Agitated Behavior Rating Scale (Woods, 1993). The therapeutic touch intervention resulted in a significant reduction in restlessness and vocalization.
symptoms compared to the placebo and usual care conditions. The placebo therapeutic touch group showed a decreasing trend in behavioral symptoms compared to usual care but there was not a statistically significant difference.

Lin, Chan, Ng, and Lam (2007) investigated the efficacy of aromatherapy in reducing agitated behavior in residents (n=70) with dementia (DSM IV) living in Hong Kong care and attention homes. This was a cross-over research design in which residents were randomized to a lavender inhalation treatment group or sunflower inhalation placebo-control group. Aroma diffusers were placed on both sides of each resident’s pillow for inhalation (1 hour minimum) during sleep over a 3 week period. Following this 3 week period, aromatherapy would be discontinued for a 2 week ‘wash out’ period. At the end of the ‘wash out’ period, the residents who had been in the lavender treatment condition would crossover into the sunflower placebo-control condition and the residents who had been in the sunflower placebo-control condition would crossover into the lavender treatment condition. The treatment conditions would then resume for a period of 3 weeks. Outcome measures included Chinese versions of the Cohen-Mansfield Agitation Inventory (CMAI) and the Neuropsychiatric Inventory (NPI) administered at pretest and posttest. At the conclusion of this study, it was found that residents in the lavender treatment group achieved significant (p<.001) reductions in their agitation scores on both the CMAI and NPI compared to the sunflower placebo-control group.

In this review of interventions that address behavior problems in nursing home residents with dementia, almost all of the studies evaluated the level of agitation in the study participants. In evaluating the level of agitation, the majority of studies used the Cohen-Mansfield Agitation Inventory (CMAI), and several other studies used measures
based on (Care Recipient Behavior Assessment; Sloane et al, 2004 & Disruptive Behavior Scale; Beck et al, 2002), or linked to (Scale of agitation intensity parameters; Kovach et al, 2004), the CMAI. The Beck et al (2002) study also evaluated the affective status of residents while the Cott et al (2002) study was one of the only studies that did not target agitation but, rather, focused on functional capacities such as communicating basic needs and ambulation. The widespread use of the CMAI is an encouraging trend in geriatric research as it provides some commonality among the disparate variables in field research.

Most of the studies reviewed in this section could be characterized as therapeutic environmental interventions. Bathing is often identified as one of the typical nursing home activities that results in agitation of the resident being bathed. Whall et al (1997) used a natural environments approach utilizing the recorded sights and sounds of nature during bathing to significantly reduce agitation in residents with dementia. Sloane et al (2004) evaluated two bathing interventions, person-centered showering and a towel bath, and found that both resulted in significant reductions in agitation compared to the usual bathing care provided in the nursing home. Although the Whall study was a quasiexperimental design without randomization, a comparison group was used to strengthen the credibility of their findings.

Other therapeutic environmental interventions that were investigated in the preceding studies include calming music, massage, bright light, and aromatherapy. Remington (2002) found that calming music and hand massage both significantly reduced agitation but there was no additional benefit in combining the two treatments. Woods et al (2005) also observed that therapeutic touch significantly reduced restlessness
and vocalizations in residents compared to control group residents. Unfortunately, Woods used a unique agitation measure while Remington used the CMAI so Woods’ findings are not as corroborative as they might have been. Lin et al (2007) used a randomized crossover design to find that lavender aromatherapy significantly reduced agitation in residents of Hong Kong care and attention homes compared to residents receiving a placebo of sunflower inhalation. Ancoli-Israel et al (2003) investigated the effectiveness of bright light treatment in reducing agitation and found that, although it delayed residents’ peak of agitation, it did not reduce it.

2.9 Interventions that address meaningful activity problems

In evaluating the well-being of individuals with dementia, the need for meaningful activities has been cited by several researchers. In their book on enhancing the quality of life for this population, Volicer and Bloom-Charette (1999) identify medical, psychological, and meaningful activities as three domains that should be addressed. Richeson (2003) references the “Need-Driven Dementia-Compromised Behavior” (p.354) model to understand agitation in older adults with dementia. For Richeson, many nursing home residents become agitated because they have an unmet need that can be ameliorated through meaningful activities such as animal-assisted therapy. In a similar vein, Cline (2006) believes that Montessori-based dementia care can reduce challenging behaviors by involving the individual and bringing meaning to their life. Recreational activity (Schreiner, Yamamoto, & Shiotani, 2005) and music therapy (Svansdottir & Snaedal, 2006) have been cited as yet additional ways to bring meaning and enhanced quality of life to nursing home residents with dementia.
In carrying out this literature review of interventions that address meaningful activities in nursing home residents with dementia, the search terms of “meaningful activities”, “dementia”, and “nursing homes” were used. The CINAHL data base produced 4 matches dating to 1999. PsycINFO produced 7 matches dating to 2000 while a search of PsycArticles resulted in a single article from 2003. The Medline data base produced 9 matches dating to 1994. A search of Social Work Abstracts identified 7 matches when the single search term “meaningful activities” was used but only one match when all three of the search terms were used.

The relatively low number of matches in carrying out this search is attributable to the “meaningful activities” search term. Unlike medical, psychological, psychosocial, and behavioral considerations, meaningful activities is not an attribute or domain that is commonly evaluated in nursing home residents with dementia. As the name states, it is an activity rather than a personal characteristic or medical condition. Most of the articles identified in this search were descriptive, theoretical, or exploratory in nature. There were very few randomized control trials or quasi-experimental research studies. As a result, most of the articles summarized in this section were identified in carrying out the literature review for the preceding sections. Generally, studies that attempted to activate, engage, and mobilize residents through activity were selected for this section. None of the studies contained the term “meaningful activities” in their title, but several authors did talk about meaningful activities as a theoretical touchstone that influenced their thinking about nursing home residents with dementia. Finally, all of the articles that were selected for this section are randomized control trials or quasiexperimental research designs.
Hopman-Rock, Staats, Tak, & Dröes (1999) tested the effects of a Psychomotor Activation Program (PAP) on cognitively impaired residents (n=92) living in 11 homes for the elderly in the Netherlands. PAP was developed for nursing home residents with dementia and it focuses on maintaining/improving communication, reactivation, resocialization, and effective functioning through a variety of recreational activities, hobbies, and activities of daily living. The PAP protocol was implemented at least twice a week for 6 months in the experimental groups while the control groups received the usual care. Whenever possible, the homes randomized groups of participating residents into experimental or control conditions. Behavioral, cognitive, and disability measures were administered at pretest and at posttest. Cognitive measures showed a significantly (p<.05) beneficial, stabilizing effect on the cognition of residents receiving the PAP intervention compared to the control group. In addition to this, some behavioral measures revealed a significant (p<.05) increase in positive group behavior among PAP residents with mild cognitive impairment.

Gerdner (2000) evaluated the effectiveness of individualized musical preferences versus classical relaxation music in reducing agitation in residents (n=39) with Alzheimer’s disease living in six Iowa long-term care facilities. This study was a repeated measures pretest-posttest design with each resident crossing over from one treatment condition into the other treatment condition. In the first treatment period, Group A residents received individualized music, and Group B received classical relaxation music. Both groups were exposed to the music for 30 minutes, two times per week for 6 weeks. After 6 weeks, there was a 2-week period in which no interventions occurred. After this 2-week “washout”, another 6-week period of music interventions
was scheduled with Group A receiving classical relaxation music, and Group B receiving individualized music. The primary outcome measure was the CMAI which was modified “to provide a more definitive assessment” (p.54) of the individualized music on the level of agitation during observation periods. During both intervention periods, the residents receiving individualized music showed significant (p<.05) reductions in their agitation scores when compared to the residents receiving classical relaxation music. This difference was observed during the 30-minute intervention and it continued through the 30-minute observation period following the intervention.

Richeson (2003) carried out a pilot study on the effects of animal-assisted therapy (AAT) in reducing agitation and increasing social interaction in nursing home residents (n=15) with dementia (MMSE<16; Medical Records diagnosis). This study used a quasiexperimental (no randomization, no control group) time-series design with three points of measurement (CMAI: baseline, posttest, and follow-up) over 9 weeks at two New England nursing homes. Certified therapy dogs, their handlers, and recreational therapists met in small groups (3-4 residents) from 2:30-3:30 PM (change of nursing shift) on Monday through Friday for 3 weeks. The primary outcome measures were the CMAI and the AAT flow sheet, “an evidence-based data collection tool” (p.355) used to measure social interaction of the participants. Following the 9-week intervention period, statistically significant (p<.001) decreases in agitated behaviors and increases in social interaction were observed following the intervention. Follow-up (3 weeks after cessation of intervention) revealed a significant (p<.001) increase in agitation which suggests that the residents’ agitation was influenced by the introduction and removal of AAT.
Schreiner, Yamamoto, and Shiotani (2005) evaluated the effect of recreational activity on the expression of positive affect in residents (n=35) diagnosed with Alzheimer’s dementia. The participating residents were recruited from the Special Care Units of two metropolitan nursing homes in western Japan. This study was a quasi-experimental research design (no control group) in which residents were randomly selected and observed using “two structured-observational instruments with demonstrated reliability and validity” (p.130). Behavior was coded by location, directed activity, facial affect expression, behavior, null-behavior, and levels of consciousness. Data was collected over 64 observation hours for each participant and activity was coded as ‘ordinary’ or ‘recreation’. Recreation (intervention condition) was scheduled activity with a certified-trained recreational therapist conducting a variety of enjoyable group exercises to engage the residents cognitively and physically. Over the course of this study, 3,854 one-minute observations were made with 75.4% of the observations made during ordinary time. Participants were observed to express happiness seven times more frequently during recreation compared to ordinary time (p<.001) and, for almost half (43.75%) of the participants, recreation was the only time that they were observed to be happy.

Holmes et al (2006) examined the differences between live music, pre-recorded music, and silent placebo periods on the apathy of residents (n=32) with moderate to severe dementia (ICD-10 diagnostic criteria) living in nursing homes and residential homes in the U.K. The presence of apathy was assessed using a specialized instrument developed for individuals with dementia (Sergio, Starkstein, Petracca, Chemersinski & Kramer, 2001). This was a randomized, placebo-controlled trial in which the observer-
rater was blinded to the condition being experienced by the participants. Participants in the study were exposed to 30-minute periods of silence, pre-recorded music, and live music in randomized order. The residents’ responses to the three conditions were filmed and rated using the Dementia Care Mapping (DCM: Kitwood, 1997) instrument. The DCM evaluates 26 activities, including apathy, using a six-point Likert scale. The DCM was the primary outcome measure for this study. A majority of the residents (69%) showed a significantly (p<.001) greater positive engagement to live music compared to pre-recorded music (25%) and the silent placebo period (12.5%). Although there was greater positive engagement with pre-recorded music than with silence, the difference was not statistically significant.

Sung, Chang, Lee, & Lee (2006) evaluated the effect of group music with movement on the agitated behaviors of elderly (≥65 years) residents (n=36) living in a 160-bed residential care facility in Taiwan. All of the residents participating in this study were diagnosed with dementia (Diagnostic and Statistical Manual of Mental Disorders, 1994 diagnosis; Stage 3, 4, 5, or 6 on Global Deterioration Scale, Reisberg, Ferris, De Leon, & Crook, 1982) and demonstrated agitated behaviors as described on the Cohen-Mansfield Agitation Inventory (CMAI: Cohen-Mansfield, Marx, & Rosenthal, 1989). Individuals randomized to the experimental group received 30 minutes of the group music with movement during the afternoon twice a week for 4 weeks. The music was a collection of familiar songs with moderate tempo (to help participants move) preferred by the majority of residents. Residents in the control condition received usual care. Agitation was measured at baseline, 2 weeks, and 4 weeks. The primary outcome measure was the CMAI, modified for the time intervals used in this study’s observational
periods. The standard CMAI looks at behavior over a 2-week period whereas the researchers in this study were interested in the immediate impact of music on agitated behaviors. After 4 weeks, agitated behaviors in the experimental group were reduced significantly (p<.001) compared to the control group.

Svansdottir and Snaedal (2006) evaluated the effectiveness of music therapy in reducing the behavioral and psychological symptoms of residents (n=38) with moderate to severe dementia (ICD-10; Stages 5-7 on Global Deterioration Scale) at two nursing homes and two hospital psychogeriatric wards in Iceland. This was a single-blinded study that randomized participants to a music therapy group or to a control group. The music therapy group met for 30 minute sessions, 3 times a week for 6 weeks while the control group received their usual care. The primary outcome measure was the Behavior Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD: Reisberg et al, 1987) which was administered at baseline (pretest), 6 weeks (posttest), and 10 weeks (follow-up). The BEHAVE-AD includes seven behavioral and affective subscales as well as a total score. Following 6 weeks of music therapy, participants in the music therapy group experienced a significant (p<.05) improvement in their combined activity disturbance, aggressiveness, and anxiety score compared to the control group. There was not a significant change in the other BEHAVE-AD subscales and, at the 4 week follow-up, the benefits of music therapy observed at the 6 week posttest had dissipated.

Ledger & Baker (2007) investigated the effects of group music therapy on agitation in nursing home residents (n=45) with Alzheimer’s disease (Stage 4, 5, or 6 on GDS; MMSE < 23). Thirteen Australian nursing homes participated in this study, and the homes were assigned (not randomized) to the treatment or control arm of the study.
This was a longitudinal repeated measures research design in which the treatment groups received music therapy once a week for 42 weeks over the course of a year. Each session of music therapy lasted from 30-45 minutes. The study participants living in the homes assigned to the control condition received their usual care. The primary outcome measure was the CMAI, which was administered prior to the intervention and at three, six, nine, and twelve months. The residents receiving music therapy experienced some short-term reductions in agitation but there were no significant differences between the treatment and control groups in respect to the range, frequency, and severity of agitated behaviors over time.

In this review of interventions that address meaningful activities, a variety of approaches have been briefly described. Recreational, music, and animal-assisted therapies have been used to improve residents’ cognition, engagement, social interaction, and affect. These therapies have also been used to decrease agitation, aggression, and anxiety. Hopman-Rock et al. and Shreiner et al. both used recreational therapy to achieve slightly different ends. In the first study (Hopman-Rock), the recreational therapy group with its emphasis on psychomotor activities seemed to stabilize participants’ cognitive performance and increase positive group behavior in participants with mild cognitive impairment. The cognitive performance of control group participants deteriorated at a significantly greater rate over the course of the intervention period. In the second study, residents in recreational therapy expressed positive affect and happiness seven times as often as when they were outside of the recreational group. In addition to this, almost all of the residents benefitted from participation in the recreational therapy group.
Music therapy was used in most (5) of the studies summarized in this section. In other studies, music has been used to increase the cooperation of residents with dementia during bathing routines (Thomas, Heitman, & Alexander, 1997), to decrease their aggressive behavior (Clark, Lipe, & Bilbrey, 1998), and to reduce disruptive vocalizations (Casby & Holm, 1994). In this review, there have been questions about live music vs. pre-recorded music to alleviate apathy (Holmes et al.) but all of the other music-related interventions were interested in the reduction of agitation. In reducing the agitation of residents with dementia, Gerdner evaluated individualized vs. classical music and Sung et al examined group music with movement. Svansdottir and Snaedal, and Ledger and Baker were interested in the immediate and long-term effects of music therapy in reducing agitation.

It is clear from these studies that, in general, music can be very therapeutic. However, there are important differences in the way music is ‘delivered’, and these differences determine how effective it will be. For example, live music is more effective than pre-recorded music in reducing apathy, and individualized music is more effective than classical music in reducing agitation. However, familiar, popular music (pre-recorded) with a moderate tempo has been used in a group to facilitate movement and this too has been effective in reducing agitation. The Ledger and Baker study on the long-term effects of music therapy on agitation was a dissenting voice in finding no difference between treatment and control groups over time. They did acknowledge some short-term reductions in agitation in the music therapy group but these differences were fleeting. It should be noted that this study scheduled the music therapy intervention just once a week in 30-45 minute sessions. The Svansdottir and Snaedal study scheduled
music therapy three times a week in 30 minute sessions and observed a significant improvement in the treatment group score of combined activity disturbance, aggressiveness, and anxiety. These findings suggest that music therapy needs to be scheduled more than once a week to be effective and that there is not a permanent or long-term benefit from this intervention.

2.10 Interventions that address family issues

Families are often intimately involved in maintaining the well-being of loved ones who are struggling with the chronic illnesses that accompany aging. In addition to the emotional comfort and support that families provide, there may be other health benefits that are associated with caring family relationships. For example, in a meta-analysis of randomized controlled trials, Martire et al. (2004) found that patients with chronic illnesses who participated in family psychosocial interventions generally had reduced rates of depression and mortality compared to patients receiving the usual medical care. This analysis included patients with a range of chronic conditions such as heart disease and cancer, but the most common condition was dementia. Although this meta-analysis did not focus on nursing homes or other long-term care facilities, the findings do support the practical and humane value of involving family members in the care of their relatives who have a chronic illness.

There have been many other studies that look more closely at the role of the family in caring for individuals with a dementing illness. Some studies have evaluated family interventions to delay nursing home placement (Dröes et al., 2000; Mittelman et al., 1996). Others have studied family involvement prior to, and following, admission to a skilled nursing facility. Port et al. (2001) examined resident contact with family and
friends before and after admission to 59 Maryland nursing homes (n=1,441). In another study, researchers looked at family contact over a five year period at Los Angeles and San Francisco nursing facilities (n=210) in an effort to understand family patterns of visitation with their relatives in long-term care (Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). All of these studies point to the importance, and to the ongoing role, of families in caring for relatives with dementia or Alzheimer’s disease.

In conducting this literature review, numerous articles were found where family members were involved in the planning and collaboration of care. There were fewer studies that directly involved the family member as part of the intervention. A search of several electronic databases using the search terms “dementia”, “family”, and “nursing home” yielded many articles over the past 20 years. The CINAHL database identified 102 articles dating to 1990. The MEDLINE database produced 151 matches dating to 1983. PsycINFO produced 115 matches dating to 1982 while PsycArticles identified just two articles. Social Work Abstracts produced 12 matches dating to 1985. Many articles were eliminated because they excluded residents with dementia or focused on caregiver/family outcomes without any evaluation of the family member with dementia. The articles that follow are the most empirically sound studies of interventions that involve the family in some capacity and identify outcome measures for residents.

Cohen-Mansfield and Werner (1997) evaluated the effectiveness of three interventions to decrease verbally disruptive behaviors in nursing home residents (n=32) with dementia. The three interventions were: 1) a videotape of the resident’s family member talking to them, 2) in vivo social interaction, and 3) music. This was a crossover research design that used a ‘no intervention’ phase as a control and as the fourth
condition to which residents could be assigned. Residents were assigned to one of these four conditions for 2 consecutive weeks. After 2 weeks, there was a “wash-out” week (no intervention conditions) before residents crossed over to the next condition. This schedule was repeated until all of the participating residents had spent 2 weeks in each of the four conditions. Verbally disruptive behaviors were measured with the CMAI and the Screaming Behavioral Mapping Instrument which was developed specifically for this study. All three interventions were significantly (p<.05) more effective than no intervention in reducing verbally disruptive behaviors. The social interaction, family video tape, and music interventions observed reductions of 56%, 46%, and 31%, respectively, in the targeted behaviors. The effectiveness of the interventions was limited to the time of the interventions as the disruptive behaviors usually resumed after the interventions were completed.

Camberg et al (1999) evaluated Simulated Presence as means to enhance the well-being of residents (n=54) diagnosed with Alzheimer’s disease and related dementias (Medical diagnosis; MMSE mean=5.1) living in nine nursing homes in Massachusetts and New Hampshire. Simulated Presence is a personalized audio tape intervention that simulates a telephone conversation in which some of the resident’s most memorable life events are recalled. This study was Latin Squares crossover design with residents “restrictively randomized” (p. 447) by facility groupings to one of 3 conditions: 1) Simulated Presence, 2) placebo audio tape of a person reading from a newspaper, and 3) usual care. Participants were in each condition for 17 days followed by a 10-day “washout”. Outcome measures included the CMAI, the Multidimensional Observation Scale for Elderly Subjects (MOSES – Pruchno, Kleban & Resch, 1988) and the Scale for
the Observation of Agitation in Persons with Dementia, a scale developed by the researchers. Simulated Presence was equivalent to usual care but significantly (p<.001) better than placebo in producing a happy expression. An analysis of staff observation logs also revealed that Simulated Presence was significantly (p<.001) better than placebo and usual care in reducing agitation. However, the outcome measures did not reflect differences in agitation, mood, or level of interest among participants in the three conditions.

Ingersoll-Dayton, Schroepfer, and Pryce (1999) studied the effectiveness of a solution-focused approach for problem behaviors among nursing home residents (n=21) with dementia (Medical diagnosis). Problem behaviors were identified as physical aggressiveness, verbal aggressiveness, or wandering. The solution-focused approach involved gathering background information on each of the residents from one family member and three certified nursing assistants (CNA) for each of the participating residents. Background information included the resident’s positive qualities, problem behaviors, exceptions to the problems and approaches used to manage them, and what behaviors family members and CNAs would expect to see if a “miracle” happened. This information was used to develop “an individualized Suggested Approaches Plan” (p. 54) for each of the participating residents. A crossover research design with randomization was used in this study with each phase of treatment lasting 7 weeks. The primary outcome measure was a modified version of the Caretaker Obstreperous-Behavior Rating Assessment (COBRA) Scale (Drachman et al., 1992). An analysis of the data revealed that family members and nurses perceived a significant (p<.05) reduction in problem behaviors over time but there was not a significant difference between the experimental
and control groups in achieving this reduction. There was also a significant (p<.01) difference between family members and CNAs in respect to their perception of problem behaviors i.e. family members viewed behaviors as less problematic.

McCallion, Toseland, & Freeman (1999) evaluated a Family Visit Education Program (FVEP) for reducing problem behaviors, depression, irritability, and withdrawal in residents (n=66) with moderate to severe dementia (MMSE<24 for high school educated residents; MMSE<19 for eighth grade educated or less; GDS>Stage 2) at five skilled nursing facilities in New York State. Residents were randomized to the FVEP (experimental) or usual care (control) conditions. The FVEP was carried out over 8 weeks and included four family group sessions and three family conferences addressing verbal communication, nonverbal communication, and effective structuring of family visits. Depression outcome measures included a subscale on the Multidimensional Observation Scale for Elderly Subjects (MOSES) and the Cornell Scale for Depression in Dementia (CSDD). The FVEP had a positive impact on depressive symptoms, particularly on the cyclic functions and ideational disturbances subscales of the CSDD. The irritability subscale of the MOSES showed a significantly lower increase in symptoms for the FVEP group compared to the usual care group. Similarly, the CMAI subscales of verbal agitation and physically nonaggressive behaviors point to significantly less agitation in the FVEP group compared to the usual care group.

Jablonski, Reed, & Maas (2005) carried out a study that examined the effect of Family Involvement in Care (FIC) on cognitive and functional outcomes in residents (n=85) with Alzheimer’s disease and related dementias (GDS – Stage 4,5, or 6) in 14 Midwestern nursing homes. This was a quasi-experimental research design that assigned
the participating homes to experimental or control conditions rather than assigning individual residents. Nursing homes were paired according to the size of their special care units, their status as a non-profit/for-profit organization, and staff turnover. The homes were then selected for assignment to experimental or control conditions, and this assignment determined whether a participating resident received FIC or usual care. The FIC intervention was carried out over a 9-month period and sought to establish a partnership between family caregivers of the participating residents and nursing home caregivers through orientation, education, partnership agreement, and follow-up evaluation. The intervention began immediately after month 3, and outcome measures were administered at baseline and at months 3, 5, 7, and 9. The measures included the Global Deterioration Scale (GDS) and the Functional Abilities Checklist (FAC), a 28-item instrument developed by two of the study investigators. The experimental group had significantly (p<.001) lower GDS scores at the end of FIC compared with their baseline scores but these scores gradually moved toward baseline levels over the course of the study. There was not a significant difference between experimental and control groups on the GDS scores, and there was no change in inappropriate behavior, cognition, or functional status observed in either group.

Garland, Beer, Eppingstall, & O’Connor (2007) evaluated the effectiveness of simulated family presence, preferred music, and a placebo condition (reading from a horticultural text) in ameliorating the agitation of nursing home residents (n=30) with dementia (Medical diagnosis; MMSE ≤ 12). A control condition of usual care was used as a comparison for these three treatment conditions. Participating residents were randomized to multiple, single-blind exposures to the treatment conditions. The
treatment periods lasted 15 minutes with observation at 2-minute intervals before, during, and after treatment for a total observation time of 45 minutes. Treatment was scheduled once a day, 3 days per week during weeks 2, 3, and 4 of the study. Residents crossed over into a different treatment condition each week, and a 2-day washout was used between treatment conditions. Outcome measures were counts of behavior as described on the CMAI. Simulated presence significantly (p<.01) reduced the frequency of physically agitated behavior compared to placebo and usual care. Preferred music was also effective in reducing physically agitated behavior and was significantly (p<.05) better than usual care but not significantly better than placebo. There was not a significant difference between simulated presence and music in reducing physically or verbally agitated behavior. In respect to verbally agitated behavior, simulated presence and placebo significantly (p<.05) reduced counts of the targeted behavior compared to usual care. Music was not significantly different than any of the conditions in reducing verbally agitated behavior.

Robison et al. (2007) evaluated the effectiveness of cooperative communication between staff and families on dementia care units at 20 Connecticut nursing facilities. Although this study was concerned primarily with improving the communication and conflict resolution skills of staff and residents’ family members, the behavioral symptoms of the residents (n=559) were also evaluated. This was a controlled trial in which each participating facility was randomly assigned the treatment or control condition “stratified by proprietary status” (p.506) for a period of 2 months. The outcome measure for resident behavior was the short form of the CMAI, which assesses 14 behavioral symptoms (agitation) of dementia (vs. 29 items on the regular CMAI). Following the
intervention period, the treatment group achieved significant (p<.05) improvement in 5 behaviors on the CMAI compared to the control group. In 7 other behavioral items drawn from the CMAI, the treatment group improved more than the control group although this difference did not reach statistical significance.

The studies summarized in this section recognize the family as an important factor in maintaining and optimizing the well-being of nursing home residents with dementia. In striving to optimize the well-being of residents, the studies generally emphasized one of two approaches. The first approach worked to improve communication, cooperation, and care planning among staff and family members. This included the Ingersoll-Dayton et al. (1999) (solution-focused), McCallion et al. (1999) (family visit education program), Jablonski et al. (2005) (family involvement in care), and Robison et al. (2007) (cooperative communication & conflict resolution) studies. The second approach used direct interventions with residents to simulate family contact. This approach was used in the Cohen-Mansfield and Werner (1997) (family videotape), Camberg et al. (1997) (simulated presence), and Garland et al. (2007) (simulated presence) studies.

Both of these approaches (improving communication and simulated family presence) had some promising findings as well as some ambiguous or disappointing findings. The McCallion et al. (1999) and Robison et al. (2007) studies both focused on the family, used the CMAI to measure residents’ agitation, and found significant improvement in the treatment groups compared to controls. A significant reduction in the subscales of verbal agitation and physically nonaggressive behavior was observed by McCallion et al. and a significant reduction in 5 agitated behaviors was observed by Robison et al. Both of these studies hoped to find benefits for the nursing staff providing
care to demented residents. Nursing staff in the Robison et al. study reported that the cooperative communication intervention brought reductions in family conflict, burnout, and depression. Following implementation of the family visit education intervention, the McCallion et al. study noted a reduction in the staff use of mechanical restraints on residents but observed that the intervention was not effective in changing the way nurses managed residents’ problem behaviors.

The Cohen-Mansfield and Werner (1997) and Garland et al. (2007) studies did not intervene directly with families or staff but, rather, focused on the residents’. Both studies evaluated the residents’ response to video/audio taped family stimuli and both used the CMAI to measure resident agitation. The Cohen-Mansfield, and Werner and Garland et al. studies both found significant reductions in agitated behavior in the treatment groups compared to controls but they also found that several placebo interventions significantly reduced agitation. Cohen-Mansfield and Werner found that the placebo interventions of in vivo social interaction and preferred music significantly reduced verbally disruptive behaviors in demented residents. The social interaction intervention was even more successful in reducing verbally disruptive behaviors than the treatment condition (family videotape). Similarly, Garland et al. found that a preferred music placebo was just as effective as simulated family presence in reducing physically agitated behavior. However, the music placebo was not as effective as simulated family presence in reducing verbal agitation and Garland et al. reported that the residents’ responses to both of these interventions varied widely. In fact, it was also observed that the placebo of someone reading from a horticultural text was significantly more effective than usual care in reducing verbal agitation. Garland et al. concluded that even the
simplest “technologies can enrich residents’ lives and alleviate distress” (p. 520). The wide variation in resident responses to different interventions supports the need to individualize interventions, as well as care, if the goal is to improve the well-being of nursing home residents with dementia.

2.11 The role of interdisciplinary teams in improving the well-being of nursing home residents with dementia

Interdisciplinary teams have been operating in an array of health care settings for decades. These teams are used to carry out assessment, crisis intervention, care planning, and treatment activities in both inpatient and outpatient settings. They may be identified as simply the “team” or use a preceding identifier such as crisis, intake, interprofessional, treatment, or multidisciplinary. The benefits of having the multiple professional perspectives of a team include a more comprehensive (Toseland, Palmer-Ganeles, & Chapman, 1986) and holistic (Sands, 2001) understanding of the client in their current life context. This comprehensive, holistic team approach has been used in settings as diverse as child welfare, mental health, and oncology to enhance problem solving and “maximize clinical effectiveness” (Jefferies & Chan, 2004, p. 210).

In many of the studies summarized in the preceding sections of this chapter, teams played an important, but almost invisible, role in working to improve the well-being of nursing home residents. The virtual invisibility of teams reflects how common they are in nursing homes rather than their lack of importance in carrying out the essential tasks of care planning and treatment. This ‘low profile’ is evident in a review of the literature on teams in the nursing home setting. A search of several electronic databases using the search terms “team”, “dementia”, and “nursing home” produced a relatively small

Many of the articles identified in this search of the literature were anecdotal or descriptive. For example, one article described an interdisciplinary team approach in long-term care (Smith, 1990) while another surveyed nursing home staff about developing their staff teams (Conroy, 2006). There were several studies that appeared to be well-done with good empirical grounding but they were oriented towards community-dwelling elders. One of these was a randomized control trial that evaluated the treatment of behavioral complications of dementia (Hinchliffe, Hyman, Blizard, & Livingston, 1995). This trial used a multidisciplinary team to formulate individualized treatment plans to be implemented in the home of the primary care provider and the individual with dementia. Another study examined the effectiveness of collaborative, interdisciplinary care for older adults with Alzheimer’s (Callahan et al, 2006). This study also focused on helping the primary care provider manage the behavioral symptoms of the family member with Alzheimer’s disease.

There were a few empirically sound studies that focused on the interdisciplinary team as an intervention to improve the well-being of nursing home residents with dementia. In the review that follows, most of the studies focused on the team as a way to reduce the behavioral and psychological symptoms of dementia. Two of the studies aimed to reduce the use of particular medications and mechanical restraints in caring for this population.
Rovner, Steele, Shmuely, & Folstein, (1996) used a randomized research design to test the effectiveness of a dementia care team in a 250-bed nursing home. In this 6-month trial, 118 residents met the eligibility criteria of a dementia diagnosis with behavior disorder. Eighty-nine residents were randomized to experimental or control conditions and, at the end of 6 months, a total of 81 completed the trial. The intervention consisted of weekly team meetings between nursing staff and a psychiatrist, regular medication reviews, and group social activities to improve care. The study team found that the treatment group experienced significant (p<.05) reductions in problem behaviors and significant (p<.056) reductions in the prescribing of antipsychotic medications, and in the use of mechanical restraints (p<.05). In addition to this, the residents in the experimental condition were more likely (p=.001) to participate in unit activities than the residents assigned to the control condition.

Schmidt, Claesson, Westerholm, Nilsson, & Svarstad, (1998) evaluated the impact of multidisciplinary team interventions on psychotropic prescribing in 33 Swedish nursing homes. In this large group of residents (n=1480), 42% had a diagnosis of dementia, 7% had a diagnosis of depression, and 5% had a diagnosis of psychosis. There were 15 homes assigned to the experimental condition and 18 homes assigned to the control condition. This randomized controlled trial made an effort to reduce the prescribing of psychotropic medications to nursing home residents through improved teamwork among physicians, pharmacists, nurses, and nurses’ assistants. Following this 12-month study, there was a significant (p<.01) decrease in the proportion of residents in the experimental group receiving antipsychotic medications. There were significant (p<.001) improvements in the use of recommended vs. nonrecommended hypnotics in the
experimental group, and the overall hypnotic prescribing rate also declined significantly (p<.05) in the homes assigned to the experimental condition. There were no significant changes in hypnotic usage in the control homes. In both the experimental and control homes, the use of nonrecommended tricyclic antidepressants decreased significantly while the use of recommended selective serotonin reuptake inhibiting antidepressants increased significantly.

Opie, Doyle, & O’Connor (2002) evaluated the effectiveness of individualized interventions developed by a multidisciplinary team to reduce the challenging behaviors of residents (n=99) with dementia (Medical diagnosis; MMSE mean=6.4) living at 42 Australian nursing homes. This was a 4-week randomized controlled trial with repeated behavioral observations based on the Cohen-Mansfield Agitation Inventory (CMAI). Residents were assigned to an early or late treatment group with the late treatment group serving as controls for the early treatment group. Interventions were developed by a four-member team that included a psychiatrist, psychologist, and nurses. Interventions utilized psychosocial, nursing, psychotropic medications, and pain management strategies. The primary outcome measure was a modified Behaviour Assessment Graphical System (BAGS: Prodger et al., 1991) that utilized the CMAI framework. Following the 4-week interventions, there were significant (0<.0005) reductions in restlessness, verbal disruption, and all behaviors combined. Significant (p<.01) reductions were also noted in physical aggression and inappropriate behaviors. These behavioral improvements were observed in the residents serving as controls as well as in the residents receiving the intervention. As a result, there was not a significant difference between treatment and control groups. The authors attribute this to a “powerful
Hawthorne effect” (p.6) that “probably reflected staffs’ positive expectations” (p.12) for this project.

Brodaty et al. (2003) compared 3 different models of care for residents (n=86) with dementia complicated by depression or psychosis. This was a 12-week randomized controlled trial with residents drawn from 11 Australian nursing homes. The 3 models of care were designated as an experimental, placebo, or control condition. The experimental condition (Psychogeriatric case management) assigned case managers to each resident to help implement a treatment plan developed by the multidisciplinary team. The multidisciplinary team was composed of “a senior registrar in psychogeriatrics, a psychologist experienced in aged care, and a registered nurse experienced in nursing home care” (p. 66). Two geriatric psychiatrists supervised treatment. The placebo condition (Psychogeriatric consultation) used the same multidisciplinary team approach but relied on regular nursing home staff to carry out the treatment plans without case management support. The control condition was the usual care that residents would receive at homes without psychogeriatric consultation. Outcome measures included 5 depression scales and 3 psychosis scales. At the end of the 12 week intervention, all participants, including controls, experienced an improvement in their depressive or psychotic symptoms. The investigators believed this was attributable to a generalization of the active intervention techniques to the control group. They also observed that the generalization of treatment effects demonstrates the difficulty in carrying out this type of research in the nursing home setting.

As noted at the beginning of this section, interdisciplinary teams are often used in health care settings to develop a more comprehensive, holistic understanding of the
client, improve problem solving, and increase treatment effectiveness. This use of the team was evident in the Opie et al. (2002) and Brodaty et al. (2003) studies where individualized plans of care were developed by the team for each resident participating in the research study. Both of these studies observed significant reductions in the problem behaviors or psychological symptoms of residents with dementia following the team-developed intervention. These positive findings were muted by improvements in the entire study population that resulted in no significant differences between experimental and control groups. This improvement in both experimental and control groups was attributed to a generalization of the treatment effects to the controls and/or a powerful Hawthorne effect in which the enthusiasm of the nursing home staffs benefitted all residents.

The Rovner et al. (1996) and Schmidt et al. (1998) studies used their interdisciplinary teams to improve teamwork and communication in the implementation of research or health policy protocols. Treatment plans were not individualized by the team and in the Schmidt et al. (1998) study, problem behaviors were not evaluated at all. The Schmidt et al. (1998) study did show how interdisciplinary teamwork could significantly change prescribing practices to meet national health policy guidelines. The Rovner et al. (1996) study demonstrated how weekly team meetings, medication reviews, and social and educational activities could reduce; problem behaviors, the prescribing of antipsychotic medications, and the use of mechanical restraints. Rovner et al. (1996) also showed how these program enhancements fostered more participation in unit activities thereby improving the lives of nursing home residents with dementia.
A careful examination of all of these studies revealed that social workers did not play a role in the interdisciplinary teams. All of the teams had nurses and physicians, or supervising psychiatrists. A psychologist served on two of the teams (Brodaty et al. & Opie et al.) and a pharmacist participated on the Schmidt et al. study team. Since nursing homes provide a lot of medical and rehabilitative care, it is understandable that physicians and nurses are often the key players on interdisciplinary teams in this setting. Although physicians and nurses play important roles on nursing home interdisciplinary teams, social workers also play an important part in planning and providing care to this population. This was evident in the AICT study where social workers were almost always involved in the planning and provision of care to residents and their families. In the studies reported on in this section, social workers were not part of the interdisciplinary teams and they were not involved in the interventions that were evaluated.

2.12 Summary of literature review on nursing home intervention studies

In reviewing the 53 articles contained in this literature review, it was found that an array of interventions were effective in reducing pain, discomfort, depression, agitation, social isolation, cognitive decline, and other behavioral and psychological symptoms of dementia. Symptoms related to pain, depression, and agitated behavior were the most frequently cited symptoms and, therefore, these symptoms will guide this summary of the literature review.

Pain can be a puzzling problem in caring for nursing home residents with dementia. Effective treatment of pain is a challenge because residents often have multiple medical conditions and their cognitive impairment interferes with their ability to
communicate accurately about what they are experiencing. In spite of this challenge, there are several studies that have used teams to effectively treat the problem of pain. Quality improvement teams (Baier et al., 2004) and an interdisciplinary treatment planning team (Cipher, Clifford, & Roper, 2007) both observed reductions in pain in residents. A Serial Trial Intervention (Kovach et al., 2006), which uses analgesics and nonpharmacological treatment in a flexible, individualized approach to care, reported that residents receiving this intervention experienced less discomfort than residents receiving the usual care. While these three studies used different interventions to address the problem of pain, all of them relied upon interdisciplinary teams to formulate and implement the interventions.

Medications were often used in these team interventions but, since medications are an integral part of the usual care provided to all nursing home residents, this facet of treatment was not evaluated in these three studies. However, there have been a few studies that have examined specific medications and dosing levels with this population. One study evaluated the effectiveness of analgesics and found that 2600 milligrams of acetaminophen/day was not adequate in reducing discomfort, especially in residents with degenerative joint disease, fractures, or back pain (Buffum et al., 2004). Another study found that 3000 milligrams of acetaminophen/day was effective in promoting residents’ social interaction and engagement in work-like activity while reducing the time they spent alone in their rooms (Chibnall, 2005). Unfortunately, a standardized pain measure was not used in this study. A third study that evaluated low dose opioid therapy observed reduced agitation but only in residents over the age of 85 (Manfredi et al., 2003). Again, no pain measures were used and agitation was used as an indicator of pain. Although
none of these studies were definitive in respect to pain mitigation, they do affirm the
importance of using an individualized approach in managing pain. The Buffum study
supports the view that many nursing home residents with dementia do not receive enough
medication to adequately treat their pain. The Chibnall study suggests that higher
acetaminophen dosing reduces pain thereby promoting social engagement and decreasing
self-isolating behavior in the nursing home environment.

Depression is another commonly-referenced problem for nursing home residents
with dementia. Many of the studies in this review reported positive findings in respect to
interventions that addressed depression, mood, and/or affect. A staff training intervention
on the psychosocial management of depression (Proctor et al., 1999), a family visit
education program (McCallion et al., 1999), wheelchair biking activity (Fitzsimmons,
2001), Snoezelen, a person-centered approach to care (van Weert et al., 2005), and
individualized care planning (Lyne et al., 2006) were all successful in reducing
depression. The Lyne study, however, observed that severely demented residents did not
have a reduction in their depressive symptoms. A similar finding emerged in a study on
emotion-oriented care, an approach that emphasizes empathy and knowledge of each
resident (Finnema et al., 2005). In this study, emotion-oriented care preserved a positive
self-image and emotional balance but only for residents with mild to moderate dementia.
The Lyne and Finnema studies point to the challenge of maintaining an individual’s well-
being as their dementing illness becomes more severe.

This challenge of maintaining an individual’s functional level has been taken up
by researchers who believe exercise and movement interventions can slow down the
progressive, debilitating effects of dementia. These strategies have aimed to reduce
cognitive decline, as well as depression, by increasing activity and engagement levels of nursing home residents. A multisensory exercise program reported an improvement in mood and activity levels (Heyn, 2003) in 13 residents with moderate to severe dementia. Two other studies featuring exercise interventions saw reductions in residents’ cognitive decline and disability scores (Stevens & Killeen, 2006) as well as in activities of daily living scores (Rolland et al., 2007). The Rolland study also evaluated depressive and behavioral symptoms but the exercise intervention had no discernable impact on these. Similarly, bright light therapy (Lyketsos et al., 1999) and pleasurable activities individualized for residents (Lichtenberg et al., 2005) were not effective in reducing depressive symptoms.

There were several other studies that looked at exercise, movement, and/or recreational activities to improve residents’ well-being but none of these studies evaluated depression. Most of these studies focused on cognition, agitation and other behavioral indicators. One study, a Psychomotor Activation Program, used movement, sporting activities, and games to stabilize cognition and increase positive group behavior in residents with mild cognitive impairment (Hopman-Rock et al., 1999). Two other studies, a group music with movement intervention (Sung et al., 2006) and exercise and walking activity (Alessi et al., 1999), were both successful in reducing agitation. The exercise and walking activity had the additional benefit of increasing the residents’ nighttime sleep while reducing their time in bed during the day. Yet another study featured recreational group exercises to engage residents cognitively and physically (Schreiner et al., 2005). This study found that participants expressed happiness seven times more frequently during recreational activity and, for almost half of the residents
participating in this study, this was the only time that they were observed to be happy. Although these exercise, movement, and recreational interventions have not been shown to reduce depressive symptoms, they seem to be effective at engaging residents, slowing cognitive decline, and, in some cases, reducing agitation.

Agitation is clearly the most frequently referenced symptom in the 53 studies covered by this literature review. Agitation is often described as behavior that is disruptive, difficult, dangerous, aggressive, and/or troublesome. In fact, the Cohen-Mansfield Agitation Inventory, a widely-used agitation assessment measure, identifies 29 behaviors that are each considered a manifestation of agitation (Cohen-Mansfield, Marx, & Rosenthal, 1989). Many studies reference problem behaviors or agitation in describing the symptoms associated with dementia, and numerous studies in this review report success in reducing these troubling behaviors. Validation therapy (Toseland et al., 1997; Deponte & Missan, 2007), sensorial reminiscence (Deponte & Missan, 2007), and Snoezelen (van Weert et al., 2005) are similar to emotion-oriented care (person-centered, empathic approach), and all three were effective in reducing problem behaviors. Another study used a person-centered approach to bathing (an event that often increases agitation in nursing home residents) and observed a reduction in agitation at bath time (Sloane et al., 2004). It is reassuring to know, that empathic, person-centered approaches to care reduce agitation because, from a social work perspective, these humane approaches to care make sense, both ethically and intuitively.

There are a variety of other interventions that use a person-centered or therapeutic orientation to reduce agitation and nurture a sense of well-being. These interventions include music, touch or massage, aroma, and animal-assisted therapies.
Music therapy (Svansdottir & Snaedal, 2006; Cohen-Mansfield & Warner, 1997), group music therapy (Ledger & Baker, 2007; Sung et al., 2006), and individualized musical preferences (Garland et al., 2007; Gerdner, 2000) were all effective in reducing agitation. Calming music and hand massage were used as independent and concurrent treatments in one study (Remington, 2002). It was found that both calming music and hand massage reduced agitation although there was no additional benefit in combining these two therapies. In another study, therapeutic touch was effective in reducing restlessness and vocalizations (Woods et al., 2005), two types of agitation frequently observed in nursing home residents with dementia. There was just one study on aromatherapy and one study on animal-assisted therapy. The lavender aromatherapy (Lin et al., 2007) and animal-assisted therapy (Richeson, 2003) studies both reported decreases in agitation with the latter also reporting increased social interaction among residents receiving animal-assisted therapy.

There were also several staff training interventions that were successful in reducing agitation in residents. One study trained nursing assistants to increase their communication skills (McCallion et al., 1999) and another study trained staff to improve their responsiveness to residents (Teri et al., 2005). The McCallion study reported a decrease in verbally agitated behavior and the Teri study reported a decrease in affective and behavioral distress. The focus of the staff training is important because there seem to be specific, rather than general, benefits following these interventions. For example, a training intervention for staff and families improved five types of agitated behavior but had no impact on seven other types of agitation (Robison et al., 2007). In another staff training study, staff was instructed on the management of depression and care planning
for residents (Proctor et al., 1999). Following this training, residents showed improvement on depression and cognitive impairment measures but not on their behavioral or activities of daily living measures. Both of these studies illustrate how staff training interventions may ameliorate specific symptoms of depression, cognitive impairment, and certain types of agitation while having no impact on more general behavioral symptoms and other types of agitation. In spite of these limitations, staff training interventions can improve the skills of direct care staff and, as a result, improve the quality of care provided to nursing home residents with dementia. However, there needs to be a strong link between the skills targeted for improvement and the instruments used to measure these skills and the impact these improved skills have on the residents.

In concluding this literature review summary, there are many interventions that have the potential to improve the well-being of nursing home residents with dementia. Training and educational interventions can be helpful to staff and families in responding to affective and behavioral distress. Person-centered, empathic approaches to care have also been successful in ameliorating depression and reducing problem behaviors. Exercise and movement activities have shown promise in engaging residents, slowing cognitive decline, and decreasing agitation. Analgesic medications are commonly prescribed to treat pain but with mixed results e.g. standard dosing practices may not be effective for residents with other chronic conditions. In conclusion, the progressively deteriorating course of dementia needs to be considered in the development of interventions for this population because the range of behavioral and psychological symptoms are influenced, if not determined, by the stage of the illness. If an intervention
is to be effective, it needs to responsive to the cognitive and functional capacities of the resident.

2.13 The role of social workers in nursing homes

The literature review in the preceding sections has covered an array of intervention studies. Many of these studies have featured social interventions as a way to improve the well-being of nursing home residents with dementia. Education and training interventions targeting staff, as well as families, and person-centered, empathic approaches to care all reflect a strong social component that is closely aligned with the beliefs, values, and activities of social work. In spite of this close alignment, none of the studies evaluated “social work” interventions and none of the studies called for social workers to carry out the interventions or activities that were part of the intervention. The literature review described numerous interventions used to improve the well-being of nursing home residents but did not shed any light on the role of social workers in these settings.

This lack of information on what social workers typically do in long-term care settings is not unique to social work practice in the United States. Two Israeli social workers have observed that “worldwide, very little empirical research has been conducted to examine how social work functions” in long-term care (Koren & Doron, 2008, p. 95). They also observed that there is a gap between the “actual” and the “ideal” social work functions in these settings. In addition to this, a recent nationwide survey in the United States revealed that there is “enormous variation in state requirements for qualifications of nursing home social workers” (Bern-Klug, 2008, p. 379). This variation in state requirements strongly suggests that there are significant differences in the social work
functions carried out in nursing homes from state to state. It is also likely that there are
disparities in the expertise of nursing home staff performing social work duties and in the
effectiveness of social work services in these settings.

In spite of this lack of empirical data on what social workers actually do in
nursing homes, it is clear that they play an important role in the day-to-day operation of
nursing homes. As noted throughout this dissertation, social workers participated on the
interdisciplinary care planning teams at the two AICT study nursing homes. Other
researchers have observed that nursing home social workers often take the lead in
working with families, recommending policy and procedural changes, and serving as the
liaison to other organizations in the community (Malench, 2004). Social workers may
also function in roles that are not typically considered social work roles. For example,
social workers have served as ombudsmen for residents and they have carried out
admissions and marketing activities on behalf of the nursing home (Arcus, 1999; Gordon,
2002).

All of these social work activities are instrumental in supporting nursing home
operations but it is not known which of these activities is most characteristic of the work
that social workers carry out in this setting. Social workers play an important role and
that role is shaped by the needs of each nursing home. For example, they may be
involved in marketing activities, not generally considered a specialty of social work,
when the nursing home is underutilized and there is a need to find more customers
(Gordon, 2002). Where there is a shortage of nursing home beds, social workers may
play a larger role in the management of admissions and coordination of discharge.
The importance of nursing home social workers has also been established through the 1987 Nursing Home Reform Act (Omnibus Budget Reconciliation Act, 1987) which mandated social work services in Medicare certified nursing homes with more than 120 beds (Simons, Shepherd, & Munn, 2008). Furthermore, the National Association of Social Workers (NASW) has recognized the important role that social workers play in nursing homes. According to NASW, social workers provide quality psychosocial care which includes services to address the social, mental health, and emotional needs of nursing home residents (NASW, 2003). Unfortunately, it is not known if this “ideal” social work role typifies what social workers actually do in nursing homes. This is an area where additional research, perhaps a survey of nursing home social workers, would begin to answer questions pertaining to the predominant role played by social workers in long-term care.
Chapter 3

Methods – Descriptive analysis

This dissertation grew out of the need to document and manage the individualized care plans formulated by the AICT for each of the residents participating in the AICT study. These documentation and management activities were not required by the organization funding this research nor were they reported on in the quarterly and final reports to the funding agency. These activities were necessary, however, to ensure adherence to the plan of care formulated by the AICT and to provide a record of identified problems and interventions. As mentioned at the beginning of chapter one (p.1), the Care Plan Review instrument was developed to document and manage these individualized care plans.

Following the completion of the AICT study, the Care Plan Review forms became the primary source of data for the follow-up analysis. This shift in the source of data was accompanied by a shift in the unit of analysis. Specifically, the unit of analysis in the AICT study was each resident whereas the unit of analysis in the follow-up was the identified problem(s) for each resident. It should also be acknowledged that this follow-up study is indebted to the AICT parent study and the quantitative analysis that was central to that study. In addition, this follow-up study borrows on some of the AICT methods because, for example, the subjects selected for the AICT study are the same subjects used for this dissertation.

In many ways, this analysis is a descriptive, exploratory accounting of what the AICT did to improve the well-being of nursing home residents with dementia. As a descriptive study, this dissertation will utilize a mixed methods approach of quantitative
and qualitative methods to address the objectives specified in chapter one (p.2).

Qualitative methods are inductive and strive to “discover important categories, dimensions, and interrelationships” from the available data (Patton, 1990, p.40).

Qualitative methods were used to carry out the following activities.

- develop categories for the problems (Objective 1)
- formulate ‘decision rules’ that clearly differentiate each of the problem categories (Objective 1)
- identify and classify the interventions used for each of the problems (Objective 4)

Quantitative methods are deductive and “collect data in the form of numbers” to describe phenomenon or answer research questions (Neuman & Kreuger, 2003, p.34).

Quantitative methods were used to:

- evaluate reliability of the problem categories (Objective 2)
- establish frequency distributions for the types of problems (Objective 3)
- establish frequency distributions for the types of interventions used (Objective 4)
- determine how effective the interventions were (Objective 5)

In carrying out this follow-up study, a more detailed description of what was actually done in the field to improve the comfort, care, and well-being of nursing home residents with advanced dementia will emerge. This will strengthen the linkage between field research and the assessment frameworks that often guide the practice of social workers and allied health professionals in the nursing home setting. These assessment frameworks were discussed briefly in chapter one (pp.11-13) and include the biopsychosocial assessment which is often used by social workers in a variety of practice settings. These frameworks should be distinguished from the Minimum Data Set (MDS) assessment and care screening forms used in most nursing homes. The MDS assessment and care screening form is a ten-page tracking document required in all long-term care
facilities receiving federal reimbursement (Medicare). Since the MDS is a required reporting form with specific questions and fields to address, its usefulness as an assessment tool to guide social work practice is limited.

3.2 Selection of subjects

The AICT study drew its subjects from two skilled nursing facilities in New York City. Both facilities are operated by the Carmelite System of Care, a faith-based organization specializing in services for the aged and the infirm. One of the AICT study homes, Ozanam Hall, is in Queens and is certified to care for 432 residents. The other home, St. Patrick’s Home, is in the Bronx and is certified to care for 264 residents. Residents were selected from three units at Ozanam Hall and from two units at St. Patrick’s Home. These particular units were selected because most of the residents on these units had a dementing illness. A total of 118 residents participated in the study; 60 residents from the three nursing units at Ozanam Hall and 58 residents from the two units at St. Patrick’s Home. St. Patrick’s Home had selected 60 residents to participate in the study but two residents withdrew and additional participants were not immediately available to replace them.

To recruit participants with advanced dementia, residents at the two homes were screened using three standardized instruments: (1) the Mini Mental State Examination (MMSE: Folstein, Folstein, & McHugh, 1975), (2) the Global Deterioration Scale (GDS: Reisberg, Ferris, de Leon, & Crook, 1982), and (3) the Activities of Daily Living Scale (ADL: Luchins, Hanrahan, & Litzenberg, 1998). To qualify for inclusion in the sample, residents needed assistance on four or more ADLs, had to score ≤23 on the MMSE, and ≥4 on the GDS. In addition, residents had to have a diagnosis of Alzheimer’s disease or
some other form of dementia and had to have family members or friends with power of attorney to sign consent forms authorizing their participation in the study. Residents with serious emergent medical conditions (e.g. aspiration pneumonia, difficulty swallowing, dehydration, or decubitis ulcers) were excluded from the study because these conditions required immediate treatment.

3.3 Study design

The AICT study was a 2x2 randomized partial crossover research design in which all nursing home residents participating in the study received the benefit of the AICT intervention. The residents were randomly assigned to treatment or control conditions at the beginning of each two-month treatment cycle, and the residents serving as controls crossed over into treatment following the two month period during which they received the usual care provided by the nursing home. Usual care included services such as medication monitoring and administration, occupational and physical therapies as medically indicated, dietary planning, assistance with activities of daily living, and social/recreational activities. Each participating resident was exposed to a single two-month treatment cycle/period, and there were a total of six treatment cycles spanning one year during the AICT project.

The follow-up analysis, which is the subject of this dissertation, will review, categorize, and evaluate the identified problems and interventions that were formulated by the AICTs as all 118 residents went through their intervention period. The identified problems and interventions for each resident were recorded on the Care Plan Review instrument. The analysis of these Care Plan Review forms will reveal the prevalence of pain, agitation, and depression (AICT dependent variables) in the target population along
with other problems that may point to a need for future research. This descriptive analysis does have a ‘post-test only’ feature that is part of the Care Plan Review instrument. The post-test on the Care Plan Review is a seven-point Likert-type scale to rate the progress made on each of the identified problems at the end of the two-month treatment cycle. Since all study participants are rated on this seven-point scale (without regard to their assignment to control or treatment conditions), this aspect of the follow-up analysis is a one-group, posttest only research design.

3.4 Interventions

The AICTs met five times (weeks 1, 2, 3, 4, and 5) during each two-month treatment cycle. Ronald Toseland and Dennis Chapman provided in-person or telephone consultation to the AICTs as care plans were developed, implemented, and monitored. Each AICT was comprised of staff from the participating units at Ozanam Hall and St. Patrick’s Home. The AICTs were interdisciplinary with professionals from medicine, nursing, nutrition, physical and occupational therapy, psychology, and social work. Residents and their families were invited to participate in a planning meeting during week 3 and in a final, wrap-up meeting during week 8.

AICTs used a holistic approach that addressed four domains of care: (1) medical/physical issues, (2) meaningful activities, (3) psychological problems, and (4) behavioral concerns. Although advanced care planning (advance directives, health care proxies, power of attorney, etc.) is another important part of a holistic approach to improve advanced illness care for nursing home residents, it was not included in AICT because both of the participating homes thoroughly addressed the advance care planning
needs of each resident during the admission and care planning process, and they update plans on a regular basis.

The AICT intervention was based on models of care developed by Volicher (Volicher, 2001; Volicher & Bloom-Charette, 1999), Toseland (McCallion, Toseland, & Freeman, 1999; McCallion, Toseland, Lacey, Freeman, & Banks, 1999), and Cohen-Mansfield (Cohen-Mansfield, Marx, & Rosenthal, 1989). Each of these models of care included at least one of the four domains addressed by the AICT intervention. These four domains of care include:

Medical/physical issues – A review was made of each participating resident’s medical conditions, level of physical pain, and medications (including psychotropic medications). A care plan was developed and implemented with the assistance of the AICT team physician and the nursing staff. The intervention plans in the medical domain included a special focus on pain management and the reduction or elimination of anti-psychotic medications that can exacerbate dementia symptoms.

Meaningful activity issues – The AICTs reviewed the activity program of each participating resident and identified new activities to maintain and enhance engagement. Activities were individualized by focusing on the pre-dementia and current interests of residents, and by talking with family members about residents’ hobbies, work-related interests, and any other preferences of residents that may not have been known by staff.

Psychological issues – A review was made of the mental health problems and symptoms of residents, as well as any emotional and family dynamic issues. Based on the review a care plan was developed and implemented.
Behavioral concerns – A review was made of agitation and other behavioral problems such as apathy that often affect nursing home residents with dementia. Participating residents’ behavior was monitored in the first two AICT meetings. Care plans were developed and implemented in conjunction with input from nurses’ aides and other direct care staff.

Usual Care (UC) – Residents in the UC condition received all the services typically provided by the facility. After two months in the UC condition, these residents ‘crossed over’ to the treatment condition where they received the AICT intervention.

This holistic, four-domain model of care served as the primary guide in assessing the needs of each resident and in developing the individualized care plans. Other models or frameworks emerged during the AICT study as the team looked at the needs of residents from different perspectives. For example, one of the frameworks was referred to as the “Five Pains” and it focused on the physical, emotional, psychological, spiritual, and familial pains of the residents. Although the “Five Pains” framework was similar to the four-domain model, it used pain as a primary lens to assess residents and it specified family as a separate, distinct domain. The assumption of pain was not pertinent in many of the study cases but, given the important role of families in the AICT project, a family domain seemed to be a useful addition to the assessment framework.

Another domain that was added to the assessment framework reflects a traditional social work perspective. Specifically, a psychosocial domain was suggested for the assessment framework during discussions with IOG staff. The addition of a psychosocial domain and family domain to the four-domain model was done after a review of the early AICT data. This review confirmed that some of the problems identified on the Care Plan
Review forms seemed to fall into family and psychosocial categories. There were also identified problems that seemed to fit into each of the other four categories. With the potential development of this six-dimensional model, there was clearly a need to define and differentiate the two new dimensions and to see how they fit with the other four dimensions.

This process of checking the early data to see if there was support for a six-dimensional model had characteristics of both quantitative and qualitative inquiry. The quantitative aspects included beginning with a set of problem categories to describe the data and counting the number of times a type of problem was observed. The qualitative aspects involved pouring through the data, which were brief narrative descriptions, to uncover new categories, dimensions, and relationships in the problems and interventions recorded on the Care Plan Review forms. This iterative process also helped in the development of decision rules to define and differentiate the six dimensions and the associated problem categories. The decision rules for this assessment framework will be detailed in the next section on measurement and measures.

3.5 Measurements and Measures

Data for the AICT study were collected by nursing and social work staff at Ozanam Hall and St. Patrick’s Home. Standardized measures were used to determine eligibility for the AICT study and to measure any changes in the level of study participants’ pain, agitation, and depression. The measures used to establish eligibility for the AICT study are shown below.

*Mini Mental State Examination* (MMSE: Folstein, Folstein, & McHugh, 1975): The MMSE has established validity and reliability as an instrument for measuring the
cognitive state of individuals. Concurrent validity with the Wechsler Adult Intelligence Scale attained Pearson $r$ scores of 0.776 (verbal IQ) and 0.660 (performance IQ). On a test-retest evaluation of reliability, the Pearson coefficient was 0.887.

*Global Deterioration Scale* (GDS: Reisberg, Ferris, de Leon, & Crook, 1982) is an instrument with a 7-stage rating of cognitive impairment. Validity of the GDS is strong as it has correlated significantly with 25 psychometric measures including CT (computerized tomographic) and PET (positron emission tomographic) scans. It is a reliable instrument as demonstrated by a test-retest correlation coefficient of 0.92.

*Activities of Daily Living Scale* (ADL: Luchins, Hanrahan, & Litzenberg, 1998). This scale was modified for the AICT study. The validity and reliability of the modified scale have not been established.

Data for the outcome measures were collected during a two-week period preceding the eight-week treatment cycle. Data were collected again during a two-week period following the treatment cycle. The outcome measures used to collect the data are listed below.

*FLACC pain scale*: The FLACC (face, legs, activity, crying, consolability) is an observational pain scale with five items rated on three-point Likert-type scales. It was completed by nursing staff on five consecutive days during each measurement period. The FLACC was originally validated with children (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997), but it has also been used in nursing home and hospice settings (Merkel, 2001). The validity of this instrument is supported by a high correlation with the Objective Pain Scale and nurses’ global ratings of pain (Merkel et al, 1997). It has also been shown to have good inter-rater reliability.
Pain in advanced dementia scale (PAINAD): The PAINAD is an observational pain scale with five categories (breathing, negative vocalization, facial expression, body language, and consolability) that are rated on a three-point Likert-type scale. It was also completed on five consecutive days during each measurement period by nursing staff. The PAINAD was developed on an inpatient special care unit for dementia and it was significantly correlated \( (r = .76) \) with the Discomfort Scale for Dementia of the Alzheimer Type providing evidence of its construct validity. It has shown adequate inter-rater reliability (Warden, Hurley, & Volicer, 2003).

Cohen-Mansfield Agitation Inventory (CMAI): The CMAI is a 29-item instrument that is used to measure agitated behaviors in elderly people. The 29 items encompass three categories of behavior: 1) aggressive behavior, 2) physically non-aggressive behavior, and 3) verbally agitated behavior. The frequency of behaviors during a two-week period of time were rated by social work staff using seven point scales ranging from (1) never to (7) several times an hour. The CMAI has excellent inter-rater reliability \( (r = .88) \) (Cohen-Mansfield, Marx, & Rosenthal, 1989).

Cornell Scale for Depression in Dementia (CSDD): The CSDD in a 19-item instrument which assesses signs and symptoms of depression in five areas: 1) mood-related signs, 2) behavioral disturbance, 3) physical signs, 4) cyclic functions, and 5) ideational disturbance. The CSDD was completed by social work staff using their own knowledge of residents and information provided by residents and staff. The CSDD has good internal consistency \( (\alpha = .84) \), sensitivity, and acceptable inter-rater reliability \( (r = .67) \), (Alexopoulos, Abrams, Young, & Shamoian, 1988).
The Care Plan Review instrument (Table 1) was developed as a tool to document and manage each of the interventions developed for the participating residents. This planned observational approach to research has been called “systematic observation” (Neuman and Kreuger, 2003, p.152). Basic identifying information, medical and psychiatric diagnoses, medications, and social-familial factors were listed on the Care Plan Review forms. In addition to this, the strengths and deficits of each resident were listed, the problem(s) targeted (Intervention Target) by the AICT were specified, and the interventions developed for each targeted problem were recorded. At the bottom of the Care Plan Review was a seven-point scale to rate the effectiveness of the AICT intervention for each targeted problem. This rating was given by the charge nurse or the supervising nurse following the eight-week treatment period. Dennis Chapman carried out all of these post-test interviews and completed all of the Care Plan Reviews during consultations with the AICTs.

As the Care Plan Reviews were being completed for each of the residents, there were ongoing discussions within the IOG about assessment frameworks and the categorizing of problems observed in the study population. It was during these discussions that the original four-dimensional holistic care model expanded to a six-dimensional model, adding a psychosocial and a family domain. With the additional domains and the increasing data on identified problems, there was a need to be clear about the definitions for these domains using the data on the Care Plan Reviews to anchor or ground this process. The creation of decision rules (Table 2) was an outcome of this process. These rules helped to define and differentiate the six domains. In creating these
### Care Plan Review

<table>
<thead>
<tr>
<th>Ozanam Hall _____</th>
<th>St. Patrick’s Home _____</th>
<th>Floor _____</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resident __________</td>
<td>Date(s) of Review __________</td>
<td></td>
</tr>
<tr>
<td>Age/Date of Birth __________</td>
<td>Admission Date __________</td>
<td></td>
</tr>
<tr>
<td>Diagnosis __________</td>
<td>Medications __________</td>
<td></td>
</tr>
</tbody>
</table>

#### Presenting Problems


#### Strengths


#### Intervention Target


#### Interventions


#### Progress Report


#### How would you rate the change in the intervention target over the last 8 weeks?

<table>
<thead>
<tr>
<th>A lot Worse</th>
<th>Moderately Worse</th>
<th>A Little Worse</th>
<th>No Change</th>
<th>A Little Better</th>
<th>Moderately Better</th>
<th>A lot Better</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
decision rules, the identified problem and the AICT intervention for that problem were compared to ensure consistency in the coding process. For example, if a problem of depression was treated primarily with an antidepressant, it was coded as a psychological issue. If social support/programming and an antidepressant were included in the treatment of depression, the problem would fall into the psychosocial domain. Likewise, if tranquilizing medications were prescribed to quell agitation, this was considered a behavioral, rather than a psychological, issue.

The decision rules were reviewed with IOG staff and, in particular, with two MSW graduate students working for the IOG. These two students agreed to participate in this follow-up study and were charged with coding all of the problems on the Care Plan Review forms using the six categories/domains delineated in the decision rules. As a preliminary check on the adequacy of the decision rules, several types of problems were identified in a small sample of Care Plan Review forms. These Care Plan Review forms were presented to the two students, along with the decision rules, to see how well the rules were able to differentiate between different types of problems. This trial run was successful as both students, working independently, were able to use the decision rules to accurately code the problems using the data on the Care Plan Reviews.

Following this successful trial, both students were scheduled to work on coding all of the problems identified on all of the Care Plan Review forms. Each of the 202 problems was numbered in an ascending numerical sequence as they appeared on the 118 Care Plan Review forms. This task was carried out by Dennis Chapman. The students generally reviewed 30 to 40 problems each week during their scheduled workdays at the IOG. The coding project was completed over a four week period. Mr. Chapman would
### Decision Rules

1. **Medical/physical Issues** – This includes treatment of medical conditions, physical pain, and Alzheimer’s-related symptoms. Medication medical issues include analgesics (Tylenol), Duragesic patch, and Aricept to name a few of the more commonly prescribed medications. A psychiatrist may be involved in consultations on medications for Medical, Psychological, and Psychosocial Issues.

2. **Psychological Issues** – A DSM diagnosis (anxiety, depression) and appropriate medication should be present for this category. **Note:** Alzheimer’s and dementia are not DSM diagnoses. For depression, medications such as Lexapro, Effexor, or Zoloft are often prescribed. If medications such as Haldol, Seroquel, or Zyprexa are prescribed, agitation or aggression may be the symptom being treated. If this is the case, it should be a Behavioral, rather than Psychological, Issue.

3. **Psychosocial Issues** – A DSM diagnosis, appropriate medications, and social interventions should be present in this category. This includes social or recreational/occupational programming that was ongoing prior to diagnosis and medication trial.

4. **Meaningful Activities** – This includes attendance at religious services, scheduled spiritual care visits, pet therapy, mobility training, folding laundry, and off-unit activities with family/friends, staff, or volunteers. A wide range of resident activities could fit into this category.

5. **Behavioral Issues** – This category includes agitated, aggressive, and repetitive behaviors. Reassurance, redirection, prompting, and distraction may be used by staff to ameliorate symptoms and/or change behavior. Activities and medication may also be used but if there is a DSM diagnosis and appropriate medications are prescribed, consider Psychological or Psychosocial Issues.

6. **Family Issues** – If the resident’s sadness or repeated requests involve family members, it should be in this category. Interventions that involve the education or actions of family members fall in this category. If a DSM diagnosis has been made and appropriate medications are prescribed, consider Psychological or Psychosocial Issues.
meet with each student weekly to collect their work and provide clarification as necessary on the use of the decision rules in coding the Care Plan Review problems. Forty-one problems out of the total 202 were selected for coding by both students in order to carry out inter-rater reliability analyses. These 41 problems (20.3% of 202 problems) were selected through a Research Randomizer program that produced 41 unique numbers in the set of numbers ranging from 1 to 202. The Research Randomizer program was accessed on the internet website http://randomizer.org/form.htm.

3.6 Data Analysis

The AICT study was an experimental research design that randomized residents to treatment (AICT) or control (UC) groups and used quantitative methods to analyze the data. The equivalence of the AICT and UC groups on baseline demographics were evaluated using Student’s t and chi-square tests. Outcome measures were analyzed using random effects regression models (RERMs) and t-tests to test for the effects of condition, time, and condition x time interaction effects. The condition x time interactions were of particular interest since these reflect significant differences between outcome variables (pain, agitation, and depression) in the AICT and UC conditions over the course of the eight-week intervention period.

The follow-up analysis describes the entire study population prior to and following the AICT treatment cycle without regard to their random assignment to treatment or control conditions. Therefore, the demographic and other descriptive data were aggregated. The inter-rater reliability study used a percentage of agreement and Cohen’s kappa (Objectives 1 & 2). Cohen’s kappa is a refinement of the straight percentage of agreement, and it “corrects for chance factors” that tend to inflate the level
of agreement (Fortune & Reid, 1999, p.241). A count of the problems recorded on the Care Plan Review forms and their assignment/coding into the six categories resulted in a frequency distribution (Objective 3). A qualitative analysis of the interventions documented on the Care Plan Review forms used an open coding process to organize and conceptualize what the AICT did in response to the six types of problems observed in the study population (Objective 4). Open coding is a method used in qualitative research to analyze and conceptualize data (Yegidis & Weinbach, 2006). The analysis and conceptualization of the AICT data in open coding produced four types of interventions;

1) medication – prescribed substances for pain, anxiety, delusions, hallucinations, and depressive symptoms. This could also include a wide array of other medications although medications for other conditions were not usually counted because they were part of usual care and not part of the AICT intervention;

2) activity – individual and/or group tasks that engage residents socially, recreationally, or in rehabilitation. Examples of activity interventions include bingo, social, cooking, and recreational groups, off-unit walks, Mass, folding napkins/laundry, watering plants, and occupational or physical rehabilitation;

3) therapy – activities that are oriented to individual residents to provide emotional comfort and support. Examples of therapeutic interventions include pastoral support and counseling, social worker/psychologist visits, pet therapy, aromatherapy, and massage/touch therapy;

4) environment – modifications to residents’ room, nursing unit, or staff behavior that help orient, prompt, or remind residents. Examples of environmental interventions include a sign to identify a resident’s room, changing room layout, and adjusting routines.
related to sleeping, rising, eating, and bathing. Other examples include staff prompting, redirection, guidance, encouragement and reassurance as well as educational efforts directed towards the resident and/or the resident’s family/significant others.

The effectiveness rating for the problems in the six categories came from the seven-point rating scale at the bottom of the Care Plan Review form. A range and mean score for each problem category was provided (Objective 5). An independent samples t-test was carried out to determine if there was a significant difference between the mean effectiveness rating scores in two problem categories. A Pearson correlation was used to explore whether there was a relationship between the average number of interventions used in each problem category and the mean effectiveness ratings for that category.

3.7 Human Subjects

The AICT study was submitted to the Institutional Review Board at the University at Albany during 2003 and, subsequently, approved during the same calendar year. The active intervention phase of this research ended in 2005 and the follow-up analysis, which did not involve human subjects, was approved through 2007 as part of the AICT project.
Chapter 4

4.1 Results: Demographics

The aggregated resident age, education, and eligibility criteria scores are shown in Table 3. The aggregation of the demographics provides yet another perspective on the study population. The average age of the residents was 86.5 years with a range spanning 33 years. Although 33 years is a fairly broad range in ages, most of the ages clustered around the mean with just two residents over the age of 98 and only one resident under the age of 73.

Table 3
Aggregate Resident Age, Education, and Eligibility Criteria

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>118</td>
<td>69</td>
<td>102</td>
<td>86.5</td>
<td>6.9</td>
</tr>
<tr>
<td>Education</td>
<td>112</td>
<td>6</td>
<td>18</td>
<td>11.2</td>
<td>2.6</td>
</tr>
<tr>
<td>Mini Mental State</td>
<td>118</td>
<td>0</td>
<td>29</td>
<td>7.0</td>
<td>7.8</td>
</tr>
<tr>
<td>Global Deterioration</td>
<td>118</td>
<td>3</td>
<td>7</td>
<td>5.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>118</td>
<td>2</td>
<td>18</td>
<td>8.3</td>
<td>4.1</td>
</tr>
</tbody>
</table>

The mean Mini Mental State Examination (MMSE) was 7.0 which reflects the advanced state of cognitive decline in most of the residents. The eligibility cutoff for the AICT study was 23 as scores ranging from 23 to 30 on the MMSE are indicative of mild to no cognitive impairment. The range of scores on the MMSE shows that there were some residents who scored above the eligibility cutoff of 23. In fact, there were three
residents who were included in the study even though they scored above this cutoff. A waiver of the eligibility guidelines was made in these three cases because each of these residents was diagnosed with dementia and their families wanted to participate in the study. Two of these residents were rated 5 (moderately severe cognitive decline) on the Global Deterioration Scale (GDS). This GDS score suggests that both of these residents were more cognitively impaired than their respective MMSE scores indicate and, therefore, both were deemed appropriate for the AICT study.

The third resident, whose MMSE score of 26 was above the eligibility threshold of 23, rated 3 (mild cognitive decline) on the GDS. This GDS rating seems to be consistent with this resident’s MMSE score of 26. This was the only resident in the entire study population of 118 residents whose GDS and MMSE scores both suggested mild/minimal cognitive impairment. In spite of these GDS and MMSE scores, this resident’s care plan indicated the presence of dementia and, as noted above, this resident’s family wanted to participate in a research study designed to improve the well-being of nursing home residents with dementia. In view of these circumstances, it was decided that although this resident did not have severe cognitive impairment it would not be ethical to exclude her and her family from the AICT study.

Table 4 shows other demographic data on the residents who participated in the AICT study. The large majority of the residents were white, Catholic women. Most were widows. A relatively small percentage of the study population had surviving spouses or had never been married. It is also worth noting that the predominant religious orientation of the residents reflects the faith-based affiliation of Ozanam Hall and St. Patrick’s Home.
Table 4
Other Demographic Data

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>114</td>
<td>96.6</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>15</td>
<td>12.5</td>
</tr>
<tr>
<td>Single</td>
<td>18</td>
<td>15.8</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Widowed</td>
<td>83</td>
<td>70.9</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>102</td>
<td>85.0</td>
</tr>
<tr>
<td>Black</td>
<td>6</td>
<td>5.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7</td>
<td>5.8</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>2.5</td>
</tr>
<tr>
<td><strong>Religious Preference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>107</td>
<td>90.7</td>
</tr>
<tr>
<td>Protestant</td>
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<td>5.0</td>
</tr>
<tr>
<td>Jewish</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td><strong>Health Care Proxy</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>103</td>
<td>87.3</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>9.2</td>
</tr>
</tbody>
</table>

4.2 Objectives 1, 2, & 3 – assessment frameworks

The reliability analysis is shown in Table 5. This analysis was done after all 202 problems had been coded including the 41 problems selected for concurrent review. Nine instances of disagreement were observed in these 41 problems. In reviewing the nine
cases of disagreement, the decision rules were used to determine if one or both of the raters made errors in coding the problems. In all nine cases of disagreement, one of the coding decisions was consistent with the decision rules while the other coding decision was not. Four of the cases involved coding a behavioral target as meaningful activities and in two cases a psychosocial target was coded psychological. The reliability analysis resulted in an observed agreement of 78% which translated into a Cohen’s kappa of .73. The closer the kappa is to 1.0, the greater the reliability. A kappa between .61 and .80 reflects “substantial” agreement between raters (Landis & Koch, 1977, p. 165).

Table 5
Cohen's Kappa Matrix

<table>
<thead>
<tr>
<th></th>
<th>Medical</th>
<th>Psych.</th>
<th>Psych-Social</th>
<th>Meaningful Activities</th>
<th>Behavior</th>
<th>Family</th>
<th>Sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>11</td>
</tr>
<tr>
<td>Psych.</td>
<td></td>
<td>4</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Psych-Social</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>
| Meaningful Activities |        | 4 | 4 | 1 | 9
| Behavior    |         |        |              | 1                    | 9        |        | 11  |
| Family      |         |        |              |                      | 1        | 1      |     |
| Sum         | 11      | 5      | 5            | 5                    | 13       | 2      | 41  |

Observed agreement: 78% (.7805)
Cohen’s Kappa: .73
The frequency of problems by category is shown in Figure 1. This distribution was observed after all 202 problems were coded into one of the six categories. The leading category with 69 problems was in the medical/physical domain. Medical/physical problems comprised 34% of the total number of problems and almost always involved the issue of pain along with an array of other physical problems. In fact, pain was evaluated in all 69 problems and, subsequently, ruled out as a problem in just
six instances. The prevalence of medical/physical problems was reflected on residents’ Care Plan Review forms where it was documented on over half (58%) of the forms. Behavioral problems were almost as common as medical/physical problems with 61 observed in this category. Behavioral problems typically involved wandering, yelling, and/or hitting, and comprised 30% of the total number of problems. Problems with behavior are often identified generically as agitation. Like medical/physical problems, behavioral problems were noted on over half (53%) of the Care Plan Reviews. Family, meaningful activities, psychosocial, and psychological problems were relatively small categories with 21, 19, 22, and 10 problems, respectively, in each. Family problems included issues of care, concern, grief, and visitation expressed by the resident or family members. Meaningful activities usually involved engaging the resident in some activity and, in two out three cases, this was spiritual/religious activity. Psychosocial and psychological problems dealt with symptoms of depression in all but two cases where persecutory delusions (psychosocial) and compulsive eye rubbing (psychological) were the primary concerns.

4.3 Objective 4 – identification and classification of interventions

Table 6 shows the type of interventions used for each of the six problem categories. There were 429 interventions developed in response to 202 problems for an average of 2.1 interventions/problem. Psychosocial problems had the highest average interventions/problem with 3.4 while family problems had the lowest with 1.4.

In the medical/physical category, medications for pain were the most common intervention with Tylenol (44) topping the list followed by Tylenol with codeine (7), Neurontin (7), Vicodan (6), and the Duragesic patch (5). Activity interventions were led
by walking programs (9) including physical therapy for ambulation and stiffness problems (1). Program activities (5), one-to-one contact (2), and attendance at Mass (2) rounded out the list. Therapeutic interventions included touch (6), aroma (4), music (4), and pet (2) therapies. Pastoral visits (1) and blue ice (1) for leg and back pain were also included in this class of interventions. Environmental interventions were comprised of regularly scheduled adjustments to residents’ seating position (3), morning stretches (1), and getting a resident out of bed later in the morning (1).

Table 6
Interventions Used in Each Problem Category

<table>
<thead>
<tr>
<th>Problem</th>
<th>Medication</th>
<th>Activity</th>
<th>Therapy</th>
<th>Environment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>77</td>
<td>18</td>
<td>18</td>
<td>5</td>
<td>118</td>
</tr>
<tr>
<td>Behavior</td>
<td>35</td>
<td>32</td>
<td>26</td>
<td>51</td>
<td>144</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>26</td>
<td>12</td>
<td>27</td>
<td>9</td>
<td>74</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>8</td>
<td>8</td>
<td>14</td>
<td>30</td>
</tr>
<tr>
<td>Meaningful</td>
<td>0</td>
<td>23</td>
<td>13</td>
<td>3</td>
<td>39</td>
</tr>
<tr>
<td>Psychological</td>
<td>16</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>24</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>154</strong></td>
<td><strong>96</strong></td>
<td><strong>94</strong></td>
<td><strong>85</strong></td>
<td><strong>429</strong></td>
</tr>
</tbody>
</table>
In the behavior problems category, environmental interventions were the most common type of intervention. These were comprised largely of staff interactions (25) with residents for the purpose of consolation, guidance, reassurance, redirection, validation, and better anticipation of residents’ needs. This included managing contact among volatile residents to maintain a safe, orderly milieu. An observation log (9) was sometimes used to monitor and manage agitation, and to understand the antecedents, context, and consequences of behavior. Other environmental interventions aimed to improve bathing and toileting practices (6), or prescribed regular repositioning (3) of residents to reduce physical stress while promoting a sense of involvement in the activities on the unit. There were also efforts to orient the residents (7) via memory and orientation boards, and to identify rooms using familiar pictures and names. Medications were frequently used to reduce agitation with antipsychotics such as Seroquel (16), Risperdol (4), Haldol (3), and Zyprexa (3) being the most commonly prescribed medications. Activity interventions included family and group interaction (15), one-to-one contact (5), attendance at Mass (5), memory support program (3) and recreational therapy (2). Therapeutic interventions included touch (7), music (4), pet (3), and aroma (2) therapies. Social work support (5) of the resident and their family, and pastoral visits (5) were also classified as therapeutic interventions.

In the category of psychosocial problems, therapeutic and medication interventions were the dominant modalities. Therapeutic interventions such as individual supportive contacts (9) were used most frequently and relied largely on pastoral visits as well as visits by a psychologist and a social worker. Pet (8), aroma (5), touch (4), and music therapies (1) were commonly used complementary approaches. Medication
interventions were used primarily for the treatment of depression with selective serotonin 
reuptake inhibiting (SSRI) antidepressants such as Lexapro (8) and Zoloft (3) being 
prescribed more often than atypical antidepressants such as Remeron (4) and Wellbutrin 
(2). There were a few interventions that used antipsychotic or antianxiety medications, in 
addition to antidepressants, to reduce agitation. There was one problem that identified 
delusions and, in this case, the antipsychotic medication Seroquel was prescribed. 
Activity interventions often specified an increase in program activities (5), attendance at 
Mass (2), one-to-one time with family, friends, or volunteers (2), and other off-unit 
activities (1). Participation in the Spanish Club was recommended for a Latino resident 
and folding bibs on the unit was programmed for another resident who liked to keep 
busy. Environmental interventions for psychosocial problems included increasing staff 
contact with residents (4) to reassure and to encourage talking and program participation. 
An observation log (2) was used to monitor smiling, agitation, and depressive symptoms 
and a communication board and hearing aid were used to help a hearing impaired 
resident.

In the category of family problems, environmental interventions were used more 
than any other class of intervention. These typically involved nursing and social work 
staff working in tandem to provide support and education (8) to residents’ families. Staff 
would also encourage, prompt, and support (5) residents (especially those residents who 
would ruminate about family) to participate in program activities and to interact with 
other residents. One environmental intervention involved staff prompting a resident to 
wear their hearing aid (to promote socialization) while another gave an Italian resident 
access to a refrigerator where family would leave spaghetti, provolone cheese, and other
foods favored by the resident. Activity interventions included visits (3) with family members or volunteers, off-unit whenever possible, and invitations to unit program activities (2). The memory support group and daily Mass were prescribed interventions for several residents with family concerns. Therapeutic interventions included supplemental social work meetings with family (3) to support and educate family members about long-term care, and to more closely assess pertinent family history. Aroma (2), touch (2), and music (1) therapies were also used in this problem category. Medications were not prescribed in response to any family issues.

In the category of meaningful activities, activity interventions were used more than any other type of intervention. Participation in Mass (10) was the most frequent intervention and this included televised services and bedside communion for several residents who were unable to leave their rooms. Program activities (4), off-unit time (3) with family or volunteers, and a cooking group (2) were also scheduled. Other activities included tactile stimulation, walking with supervision, and memory support. Therapeutic interventions to address meaningful activities were regular pastoral visits (7), pet (4), and touch (2) therapies. Environmental interventions consisted of putting together a photo album/memory book to support a resident’s recollection of family and friends (1). Another intervention posted a wandering resident’s name and photograph outside of her room in an effort to reduce wandering (1). Staff attention was another environmental approach used to reduce screaming in a perpetually distressed resident immobilized with chronic pain (1). Medications were not prescribed as an intervention to address meaningful activities.

In the category of psychological problems, medication interventions were used
more frequently than all of the other interventions combined. As observed in the
treatment of psychosocial problems, the SSRI antidepressants Lexapro (5) and Zoloft (1)
were prescribed more often than the atypical antidepressants. The antipsychotic
medications of Zyprexa (3), Seroquel (2), and Risperdol (1) were usually prescribed to
decrease agitation and anxiety in residents who were already being treated for depression.
There were two cases in which delusions were a past or present problem. In both cases
antidepressants and antipsychotics were prescribed concurrently. It should be noted that
the resident who had problems with delusions in the past remained symptom-free during
the intervention period and, as a result, the antipsychotic medications were discontinued.
Activity interventions included program (2) and recreational activities (1).
Environmental interventions used observation logs (2) to monitor compulsive eye
rubbing and frowning (depressive symptom). Another environmental approach involved
staff offering a resident snacks and distracting her with a doll to stop her from eating the
buttons on her clothes. Therapeutic interventions were comprised of music (1) and pet
(1) therapies.

4.4 Objective 5 – effectiveness of interventions

Table 7 summarizes the change ratings on the intervention targets (problems) for
each of the six problem categories. The change ratings were drawn from the 7-point
rating scale that followed each target problem on the Care Plan Review forms. There
were no problems that were rated “1” (a lot worse) or “2” (moderately worse) so these
ratings were not shown in the table. Similarly, problem rating “3” (a little worse) was not
included in Table 8 because there was just one problem that received this rating. The
only problem that received this rating was for pain (medical problem) experienced by a
resident with multiple sclerosis, Parkinson’s disease, and urinary tract infection. This resident’s pain was exacerbated by her vegetative condition which required that she be physically repositioned every two hours. All of the other 201 problems received a rating ranging from “4” (no change) to “7” (a lot better).

Table 7
Change Ratings by Problem Categories

<table>
<thead>
<tr>
<th>Problem</th>
<th>n</th>
<th>No Change 4</th>
<th>A little Better 5</th>
<th>Moderately Better 6</th>
<th>A lot Better 7</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>68</td>
<td>14</td>
<td>6</td>
<td>36</td>
<td>12</td>
<td>5.6</td>
</tr>
<tr>
<td>Behavior</td>
<td>61</td>
<td>15</td>
<td>12</td>
<td>20</td>
<td>14</td>
<td>5.5</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>22</td>
<td>2</td>
<td>1</td>
<td>15</td>
<td>4</td>
<td>6.0</td>
</tr>
<tr>
<td>Family</td>
<td>21</td>
<td>4</td>
<td>3</td>
<td>10</td>
<td>4</td>
<td>5.7</td>
</tr>
<tr>
<td>Meaningful</td>
<td>19</td>
<td>6</td>
<td>4</td>
<td>6</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>Psychological</td>
<td>10</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>5.4</td>
</tr>
<tr>
<td>Total</td>
<td>201</td>
<td>43</td>
<td>29</td>
<td>91</td>
<td>38</td>
<td></td>
</tr>
</tbody>
</table>

Psychosocial problems received the highest average posttest score (6.0) with 68% (15) of the 22 psychosocial problems receiving a “moderately better” rating. All of the problems in this category were for depression except in one case where persecutory delusions were documented as the primary problem. The lowest average posttest score
(5.3) was received in meaningful activities with 32% (6) of the 19 problems receiving a “no change” and 32% (6) receiving a “moderately better” rating. At least half of the target problems that were categorized in meaningful activities were spiritual in nature and involved residents’ interest in attending Mass. A variety of other issues including irritability, agitation, loss of walking or talking skills, depressive symptoms, and quality of life were noted in this problem category. In respect to all of the problems, some improvement was observed in 78% (rating > 4) of the posttest ratings while no change or worsening of the problem was observed in 22% (rating ≤ 4) of the ratings.

As part of the analysis for this dissertation, the Care Plan Review forms were reviewed to identify all of the physically non-aggressive behaviors (wandering, restlessness, pacing, repetitive vocalizations). Out of the 61 behavioral problems recorded on the Care Plan Review forms, 25 were identified as physically non-aggressive behaviors. When the change rating is computed for these 25 problems as a subset of the total 61 behavior problems, the change rating increases from 5.5 to 5.7 (not shown in Table 7). This higher, more favorable change rating for physically non-aggressive behavior problems is consistent with the significant finding on the physically non-aggressive subscale of the CMAI in the AICT study. This also supports the idea that despite the bias and social desirability factors inherent in the change ratings given by nursing staff, their ratings are credible and mimic the results obtained on the CMAI.

Depression was the third most common problem addressed in the AICT study and it was always coded as a psychosocial or psychological problem. As noted above, 68% of the interventions in the psychosocial category were rated ‘6: moderately better’ while in the psychological category, just 40% of the interventions achieved this rating. This
difference was reflected in the mean change rating where psychosocial problems averaged 6.0 while psychological problems averaged 5.4. An independent samples t-test was carried out to compare the change ratings for psychosocial (M=6.0, SD=.82) and psychological (M=5.3, SD=1.0) problems. Although the difference between these two categories approached significance, it did not reach the .05 significance level (t=1.88, p=.07).

It is interesting to note that the psychosocial category also had the highest number of interventions per problem averaging 3.4 while the psychological category was a distant second with 2.4 interventions per problem. This prompts the question, “Is there a relationship between the number of interventions and change rating scores?” The answer to this question appears to be “No” as the categories with the second and third highest change ratings (family and medical/physical) had the lowest number of interventions per problem averaging 1.4 and 1.7 respectively. The absence of a relationship between change ratings and the number of interventions was confirmed by an analysis using Pearson product-moment correlation coefficient (r=.096, n=202, p=.172).

4.5 Summary of Results

In summarizing the findings presented in this chapter, the Cohen’s kappa matrix shown in Table 5 is the result of coding all of the AICT problems into six categories and carrying out an inter-rater reliability analysis on the problem categories (Objectives 1 & 2). The observed agreement between raters was 78% and the Cohen’s kappa was .73. The kappa of .73 falls in the range of substantial agreement (.61-.80) for the six categories/dimensions. The Figure 1 bar graph shows the frequency of problems in the six problem categories (Objective 3). The dominant problems in the study population
were medical and behavior, comprising 34% and 30%, respectively, of the total number of problems. The least reported problem category was psychological comprising 5% of the total number of problems. Table 6 shows the number of interventions by type (medications, activity, therapy, and environment) used in each of the six problem categories (Objective 4). Medication interventions were the most common, accounting for 36% of the interventions used in the AICT study. The balance (64%) was almost equally divided among activity, therapy, and environmental interventions. Table 7 shows the posttest change ratings across the six problem categories as reported by the supervising and charge nurses on the units where the participating residents lived (Objective 5). All of the problem categories averaged between 5 (A little Better) and 6 (Moderately Better) on the 7-point change rating scale. An independent samples t-test revealed that there was not a significant difference between the psychosocial and psychological mean change scores. A Pearson correlation was carried out and it confirmed that there was not a relationship between number of interventions used and the change ratings in the six problem categories.
Chapter 5

5.1 Discussion

The five objectives of this dissertation provided a way to describe and analyze the problems and interventions that emerged during the AICT study of nursing home residents with dementia. The first three objectives involved: 1) categorizing the observed problems, 2) carrying out a reliability analysis on the categories, and 3) creating a frequency distribution of the problems for each a category. These three objectives, which will be discussed in the next section (5.2), helped to determine if a proposed six-dimensional assessment framework would be a useful tool for practitioners, especially social workers, in the nursing home practice setting. The fourth objective, which will be discussed in section 5.3, identified and classified the interventions used in the AICT. The fifth objective, which will be discussed in section 5.4, rated the effectiveness of the interventions. This chapter will conclude with a discussion of the implications for future research and social work practice.

5.2 Objectives 1, 2, & 3 – assessment frameworks

From the beginning and throughout the AICT study, the assessment of each resident was guided by a holistic approach. As reported earlier, this holistic approach began with a four-dimensional framework that addressed the medical/physical, meaningful activities, psychological, and behavioral aspects of each resident. However, as each resident’s needs were assessed, the four-dimensional framework seemed limited and was often adjusted. At times the assessment process resembled the traditional biopsychosocial assessment used by social workers. At other times, a spiritual concern or family issue shaped the care plan which suggested the importance of adding these
dimensions to the assessment framework. For the purposes of this dissertation, it was decided to test the usefulness of a six-dimensional framework that added psychosocial and family dimensions to the original four-dimensional model. This six-dimensional framework was defined by the decision rules outlined in the methods chapter (Table 2, p.107) and guided the coding of all the target problems into the six domains/categories (Objective 1).

During the development of the decision rules and the coding process, the differentiation among some of the categories seemed less clear-cut than when the decision was made to create a six-dimensional framework. For example, there was very little difference between psychosocial and psychological categories but, in the end, it was decided to retain these two categories rather than consolidating them into a single psychological or psychosocial category. The decision to keep both categories, in hindsight, was a mistake influenced by the fact that depressed residents were being treated with medications alone (psychological) or with medications and social support (psychosocial). This differentiation was articulated in the decision rules and provided a basis for the psychological and psychosocial categories. Although these two categories can be differentiated, it now seems that this differentiation is unnecessary or artificial.

In a similar way, family was added as a separate domain in the six-dimensional assessment framework. In retrospect, this also seems like a spurious decision. Consider that in the biopsychosocial assessment used by social workers, family is a secondary or sub-category even though it is always an integral part of the assessment. Family is undoubtedly an important consideration in the assessment process but it is readily subsumed within the three-dimensional framework of the biopsychosocial assessment.
For example, family considerations are always addressed in assessing the biological, psychological, and social aspects of an individual’s history and life context. Family was retained as a discrete category because the involvement of families was an important part of the AICT study and an early review of the data suggested that family issues would be more prevalent than they actually were.

The reliability analysis (Table 5, p.115) provides another perspective on the usefulness of the six-dimensional assessment framework (Objective 2). The analysis highlights the points of disagreement in assigning categories while, overall, providing some support for the six-dimensional model. Some of the disagreement could be attributable to fatigue or inattentiveness in one of the raters. An inspection of the problems where there was disagreement confirmed that one of the raters erred in using the decision rules in coding several problems. In this case, the disagreement was not the result of two similar categories or ambiguity in the decision rules. To be fair, there was ambiguity in some of the care plan review forms that the raters used to make their coding decisions. Each problem documented on the care plan review forms had notes from the AICT meetings that addressed the identified problem, the interventions, and the progress made during the 8-week intervention period. These care plan review notes did not always clearly point to a particular problem category and, if the decision rules were not assiduously followed, mistakes could easily occur.

A third perspective on the six-dimensional framework is provided by the frequency distribution (Table 6, p.116) of the target problems observed in the study population (Objective 3). A count of the target problems is yet another way to evaluate the usefulness of the categories in this six-dimensional model. The assumption here is
that, in general, the more problems identified in a particular category, the more useful, the
more relevant that category would be in assessing the study population. In the AICT
study, medical/physical (pain) and behavior (agitation) problems comprised almost two-
thirds (64%) of all of the problems. These two categories are clearly relevant for nursing
home residents with dementia and should, therefore, be part of an assessment framework.

Psychosocial problems were a distant third in the frequency count comprising
11% of the observed problems. Almost all (95%) of the psychosocial problems
addressed depression. This is similar to the psychological category where nine of the 10
problems involved depression. With just 10 problems, the psychological category was
the smallest of the six categories comprising just 5% of the total number of problems
identified in the AICT study. As noted earlier, the similarity of these two domains begs
the question - are these two domains or one? In addition to this, the small number of
cases in the psychological category argues for consolidation into one psychosocial
domain. Combining these two categories would increase the frequency of psychosocial
problems to 32, and increase the share of psychosocial problems to 16% of the total
problems observed.

The two remaining categories, meaningful activities and family, each make up
about 10% of the total number of observed problems. These two categories have a wider
array of problems and are less homogeneous than the other categories. For example,
meaningful activities addressed spiritual matters in about half of the cases but, in other
instances, dealt with irritability, depressive symptoms, apathy, wandering, and loss of
expressive and/or ambulatory skills. Many of these issues could have, ostensibly, been
assigned to other problem categories. Recall that this ambiguity in assigning problems to
categories tripped up one of the graduate assistant raters as she was carrying out her coding tasks for the reliability analysis (four problems coded as meaningful activities should have been coded as behavior problems). Problems such as depressive symptoms, apathy, and spiritual longing could fall within the psychosocial domain while irritability and wandering seem to fit in the behavioral domain. The relatively small number of meaningful activity problems, along with the array of problems that could be assigned to other categories, weakens the case for meaningful activities as a distinct domain.

The family category had an array of problems that could have been categorized as medical/physical, behavioral, or psychosocial. For example, one family problem involved a resident who repeatedly called out for her son. Although this behavior could be symptomatic of depression (psychosocial) and/or agitation (behavioral), the decision rules determined that the recurrent calling out for her son amidst her distress made this a family issue. Another family issue focused on a resident’s husband who would yell at her when she was unable to respond to his questions. She had recently suffered a stroke and, in this case, the AICT called for staff to provide emotional support and education about stroke to the frustrated husband. The provision of emotional support suggests a psychosocial issue while education about stroke suggests a medical/physical concern. This ambiguity in the family category came up in the reliability analysis where a family issue was coded as meaningful activities. This particular problem was probably coded as meaningful activities because the resident was involved in a daily memory support program that seemed more pertinent to her well-being than the family visitation issue which was intermittent and more difficult to change. As in the meaningful activities
category, the small number of family problems and the heterogeneity of these problems weaken the case for a discrete family domain.

In reviewing the first three objectives, there is limited support for a six-dimensional assessment framework. The six-dimensional model doesn’t offer a clear advantage to the traditional biopsychosocial assessment or the four-dimensional model (medical/physical, meaningful activities, psychological, and behavioral) used in the AICT study. The psychosocial and psychological categories turned out to be redundant and could be consolidated into a single psychosocial domain. The meaningful activities and family categories captured important issues but these issues were a small percentage of the total number of problems and could have been part of the broader medical/physical, behavioral, or psychosocial domains. Meaningful activities could easily be part of the behavioral domain although spiritual needs, which were part of meaningful activities, would fit better within the psychosocial domain. Family issues could also be subsumed within the psychosocial domain. These changes would result in a framework with three primary dimensions of medical/physical, psychosocial, and behavioral. Meaningful activities and family issues would be subsets or secondary elements within the psychosocial or, in some cases, medical/physical domains.

5.3 Objective 4 – identification and classification of interventions

The next piece of this analysis is the identification and classification of interventions (Objective 4). The large number and wide array of interventions reflect an individualized, multifaceted approach to improving the well-being of nursing home residents with dementia. Many of the interventions were ongoing when the AICT care plans were initially developed while other interventions were a direct result of the AICT
process. This combination of ongoing and added AICT interventions was evident in the
treatment of pain and depression where medications were, in most instances, already
being used when the AICT plans were developed. The AICT did advocate for changes in
dosing and medications while adding other interventions to each resident’s care plan in
an effort to ameliorate an identified problem.

In respect to pain problems (medical/physical), most (65%) of the interventions
were medications for management of pain. The reliance on medications to manage pain
is similar to many of the studies cited in the chapter 2 literature review of interventions
that address medical/physical problems (p.33). For example, two of the studies (Buffum
et al., 2004; Chibnall et al., 2005) used analgesics and a third (Manfredi et al., 2003) used
opioids as the primary intervention. All of the others used a flexible mix of interventions
to manage pain including two studies (Kovach et al., 2006; Cipher et al., 2007) that, like
the AICT study, individualized treatment to nursing home residents.

Medications were also the most frequently used intervention in treating
depression in the AICT residents. Selective Serotonin Reuptake Inhibiting (SSRI)
antidepressants were the most commonly prescribed medications in both psychosocial
and psychological categories where depression was the dominant problem. The
psychosocial category included medication and social support interventions in treating
depression and resulted in an average of 3.4 interventions/problem, the highest average
across the six problem categories. The decision rules for the psychosocial category
reflect the common practice of using medications and supportive therapy in treating
depression, and this two-pronged approach was used twice as much as medications-only
in treating AICT residents diagnosed with depression.
In the chapter 2 literature review on interventions that address psychological (p.41) and psychosocial (p.50) problems, interventions featured exercise (Heyn, 2003; Rolland et al., 2007; Stevens & Killeen, 2006), wheelchair biking (Fitzsimmons, 2001), bright light (Lyketsos et al., 1999), staff training (Proctor et al., 1999; Teri et al., 2005), validation therapy (Toseland et al., 1997; Deponte & Missan, 2007), emotion-oriented care (Schrijnemaekers et al., 2001; Finnema et al., 2005) and individualized care planning (Lyne et al., 2006). One study individualized pleasurable activities to shape the behavioral management and treatment of nursing home residents (Lichtenberg et al., 2005). The individualizing of care was also done in the AICT but it is about the only similarity that it shares with the literature review studies. It should also be noted that none of the literature review studies used antidepressant medications as part of their intervention.

Agitation is another area that was targeted by many of the AICT interventions. As noted in preceding sections, agitation was the second most common problem in the AICT study following pain. Unlike the problems of pain and depression, agitation was treated primarily through nonpharmacological interventions such as guidance, reassurance, and redirection from staff. Behavior observation, memory boards, environmental cues, schedule adjustments, activities, and individual contact were all used as interventions to reduce agitation. Medications were also used to reduce agitation but comprised just 24% of all the interventions in this category. Multiple interventions were common in addressing agitation/behavior which contributed to an average of 2.4 interventions/problem in the behavior category, the second highest intervention/problem ratio across the six categories.
The chapter 2 literature review on interventions that address behavior problems (p.61) cited 10 studies. All of these studies used nonpharmacological interventions, most of which had therapeutic and/or environmental characteristics. The studies that used environmental interventions included the communication skills program for nursing assistants (McCallion et al., 1999), bright light (Ancoli-Israel et al., 2003), and person-centered bathing techniques (Sloane et al., 2004). The therapeutic intervention studies included therapeutic touch (Woods et al., 2005), calming music and hand massage (Remington, 2002), and aromatherapy (Lin et al., 2007). There were also studies that emphasized activity interventions with therapeutic or environmental elements e.g. ADL and psychosocial group activities (Beck et al., 2002), walking and talking groups (Cott et al., 2002), physical activity and environmental modification (Alessi et al., 1999), and individualized balancing of calming and stimulating activities (Kovach et al., 2004). The AICT used many interventions similar to these including aroma, music, physical, and touch therapies, group psychosocial activities, and environmental modifications. AICT interventions were almost always used in combination with other interventions to create an individualized care plan for each resident.

The identification and classification of interventions used in the AICT study and in the chapter 2 literature review provided a way to describe the many interventions used with nursing home residents with dementia. Some researchers (Bharani & Snowden, 2005; Camp, Cohen-Mansfield, & Capezuti, 2002; Turner, 2005) have described interventions with this population as either pharmacological or nonpharmacological. Others have used the term ‘psychological’ (Logsdon, McCurry, & Teri, 2007) or ‘psychosocial’ (Verkaik, van Weert, & Francke, 2005) to describe an array of
nonpharmacological interventions. The limitations in classifying interventions become
evident when trying to pigeonhole interventions that fall into two categories e.g. group
music therapy with movement (Sung et al., 2006). Likewise, interventions such as
psychosocial group activities could have an activity or a therapeutic orientation.

The classification of interventions does have some usefulness as a heuristic tool.
In reviewing the intervention table (Table 7) on page 118, one can quickly determine that
medications were the most frequently used intervention in treating medical and
psychological problems while medication and therapeutic interventions were used
equally in addressing psychosocial problems. It can also be seen that environmental,
activity, and therapeutic interventions (i.e. nonpharmacological) were used three times as
frequently as medications in addressing behavioral problems. This is a reassuring finding
that speaks to the ethical, measured use of medications at the two nursing homes where
the AICT study was carried out.

In the past, the use of medications as a chemical restraint in managing the
behavior of nursing home residents was a practice that led to the passage of the Nursing
Home Reform Act of 1987 (Omnibus Budget Reconciliation Act, 1987). This act
prohibited the use of chemical restraints to control behavior and it also established
regulatory guidelines to improve the quality of care for nursing home residents. Quality
of care and quality of life concerns are central to the role of social workers in these
settings. Social workers are well-positioned to improve the quality of care and quality of
life for nursing home residents with dementia because they develop a comprehensive
understanding of the person in their unique life context. In addition to this, social
workers have the responsibility of working with each resident’s family to better
understand the needs of the resident and their family. This understanding of the resident and their family informs quality of care and quality of life questions that frequently arise in the nursing home.

5.4 Objective 5 - effectiveness of interventions

The last objective (5) in this dissertation will include a review of the effectiveness of the AICT interventions and the interventions described in the chapter 2 literature review. The AICT intervention effectiveness is summarized in Table 7 on page 130. The posttest rating for each of the 202 problems was based on a 7-point scale. The rating for each problem was given by the charge nurse or supervising nurse on the unit where the resident lived. The table shows a range of four ratings rather than seven because only one of the 202 problems received a rating lower than ‘4-No Change’. This absence of low ratings, which would point to a failure of the interventions or to the deterioration of the resident, is striking. Part of this may be due to the eligibility process that screened out residents who had more emergent or acute medical problems. The absence of low ratings could also reflect a social desirability factor in which the nurses involved in the AICT research wanted outcomes that matched the expectations of the study i.e. that the well-being of the residents would be improved through interventions developed for each of the identified problems.

In the paragraphs that follow, a brief discussion of the intervention effectiveness will focus on the problems of pain, agitation, and depression which accounted for most of the AICT problems. These three problem types were captured by the physical/medical, behavioral, and psychosocial or psychological categories respectively. In the AICT parent study, there were standardized measures for pain, agitation, and depression. The
change in scores from pretest to posttest on these measures will serve as benchmarks in comparing the posttest ratings given by nursing staff in this follow-up evaluation. The findings of the chapter 2 literature review on the effectiveness of various interventions in reducing pain, agitation, and depression will also be referenced as appropriate to give additional perspective on the treatment of this symptom triad.

In the AICT study, pain was the most frequently cited problem and it was always coded as a medical/physical problem. In the posttest ratings, over half of the pain problems were rated ‘6: moderately better.’ However, about 20% of the problems were rated ‘4: no change’ which brought the mean score for the category down to 5.6. Still, this is a favorable mean change rating and it is consistent with the findings on the FLACC and PAINAD scales used in the AICT study. On the FLACC and PAINAD measures, there was a significant decrease in the scores from pretest to posttest indicating a reduction in pain over time for both treatment and usual care groups. It is likely that there was a generalization of treatment effects that decreased the pain scores for the usual care group. This may have been attributable to the fact that the nurses who worked on the AICT provided care for residents in both treatment and usual care conditions. The increased focus on reducing pain in residents assigned to the treatment condition probably spilled over to the care provided to residents receiving usual care. This spillover also seems likely because medications and medication management were the most frequently used intervention to ameliorate pain for all residents as well as for the residents assigned to the AICT treatment condition.

Using medications as the primary intervention for pain is a common practice in nursing homes. However, as noted in the chapter 2 literature review (interventions that
address medical/physical problems), medications are not always effective in reducing pain and other related symptoms. In medication only studies, Manfredi et al. (2003) observed a reduction in agitation but only in residents over the age of 85 while Chibnall et al. (2005) observed an increase in social interaction for residents in an acetaminophen treatment group. Although these were positive findings, neither of these studies used pain measures but, rather, used agitation as an indicator of pain. Buffum et al. (2004) did use a standardized pain measure in their trial and found that neither prn (as needed) nor regularly scheduled doses of acetaminophen up to 2600 mg/day reduced pain in demented residents with chronic conditions such as degenerative joint disease, fractures, or back pain. The two studies that individualized treatment (Cipher et al., 2007; Kovach et al., 2007) found significant reductions in pain. It should be noted, however, that the Cipher study did not use medications and was a quasi-experimental study (no control group) that evaluated multimodal cognitive behavioral therapy. The AICT study did not use cognitive behavioral therapy but an individualized approach was used to significantly reduce pain in the participating residents. Pain was aggressively treated with analgesics and opioids at both AICT nursing facilities and this undoubtedly contributed to the significant reductions in pain for the residents who participated in the study.

Agitation was the second most common problem addressed in the AICT study and it was always coded as a behavioral problem. Only about one third of the interventions in this category were rated ‘6: moderately better’ and the category had a mean rating of 5.5. It should be noted that virtually all of the behaviors documented in the care plan review forms are described by the 29 types of agitation specified on the three subscales of the CMAI. In the AICT study, agitation scores dropped significantly for both treatment and
control groups. The most noteworthy finding in this analysis was on the physically non-aggressive subscale of the CMAI which showed that the treatment group agitation scores decreased significantly more than the control group. This was the only finding in the parent study that clearly supported the hypothesis that residents assigned to AICT would experience significant reductions in pain, agitation, and depression compared to residents who received the usual care.

Almost all of the studies in the chapter 2 literature review on interventions that address behavior problems measured agitation and most, like the AICT, used the CMAI or CMAI-based instrument to measure agitation. Significant reductions in CMAI scores were observed in evaluations of nursing assistant communication skills (McCallion et al., 1999), calming music/therapeutic touch (Remington, 2002), person-centered bathing (Sloane et al., 2004), balancing activities (Kovach et al., 2004), aromatherapy (Lin et al., 2007) and an exercise and walking program (Alessi et al., 1999). Bright light therapy (Ancoli-Israel et al., 2003) was not effective in reducing agitation and a walking and talking program (Cott et al., 2002) was unable to show improvement in communication, mental organization, physical disability, socially irritating behavior, or disengagement. Two of the above studies (Alessi et al. & Cott et al.) did not use the CMAI so their outcomes cannot be readily compared to many of the other studies that used the CMAI. In spite of this, there are numerous interventions that have been effective in reducing agitation. An individualized approach (Sloane et al., 2004; Kovach et al., 2004), such as that used in the AICT study, is supported by research and, as a general principle, could be integrated into a variety of interventions to improve the well-being of nursing home residents with dementia.
Depression was not as common as pain or agitation in the AICT study but it was diagnosed and treated in almost a quarter (24.5%) of the residents. This finding contrasts sharply with the small number of depressive symptoms recorded on the CSDD at pretest and posttest. As noted at the beginning of this chapter, the lack of depressive symptoms on the CSDD was a curious finding and it created a floor effect whereby it was not possible to measure any reduction in depressive symptoms in the study population. The CSDD is a reliable, validated measure of depression and its identification of a relatively small number of depressive symptoms in the AICT study is probably attributable to lapses in the way it was administered. Specifically, the CSDD requires two interviews (one with the client and one with the care provider) each time it is administered. The staff responsible for completing this measure had many competing demands on their time and almost certainly didn’t carry out two interviews at the specified times.

As a result of this lapse in the administration of the CSDD, the scores on this measure cannot be used as benchmark or criterion for the change ratings in the psychosocial and psychological categories. In considering the favorable change rating of 5.4 in the psychological category, it does seem likely that the residents receiving antidepressant medications experienced some improvement in their depressive symptoms. It also seems likely that residents who received antidepressant medication and social therapeutic support (psychosocial category) experienced a greater improvement in their depressive symptoms as reflected in the higher change rating of 6.0 although there is not a statistically significant difference in the change ratings of psychosocial and psychological problems.
In the chapter 2 literature review on interventions that address psychosocial and psychological problems, none of the studies featured medications as an integral part of the intervention. In fact, depressive symptoms were evaluated in only half of the studies as a range of other dementia-related symptoms (behavior, cognition, disability, quality of life, and sleep to name a few) were often selected for evaluation. In respect to the studies that did focus on depression, Spector et al. (2001) used reality orientation and cognitive stimulation to help a treatment group achieve significant reductions in depression compared to a control group. However, in a similar but larger follow-up study, Spector et al. (2003) found no difference between treatment and controls on depression. Finnema et al. (2005) evaluated integrated emotion-oriented care and, like the Spector et al. (2003) study, found no difference between treatment and controls on depression measures. Staff training (Teri et al., 2005; Proctor et al., 1999), recreational wheelchair biking (Fitzsimmons, 2001), person-centered a.k.a. ‘Snoezelen’ (van Weert et al., 2005), and individualized care planning (Lyne et al., 2006) all observed significant reductions in depression. The only studies that were similar to the AICT study were the ‘Snoezelen’ (van Weert et al., 2005) and individualized care planning (Lyne et al., 2006) studies. These projects were similar to the AICT study in that they adjusted their interventions to fit the needs and preferences of the participating residents. Using an individualized approach to care is ethical, respectful, and consistent with social work values. These studies also demonstrate that individualized care can be effective in ameliorating the depressive symptoms associated with dementia.
5.5 Future research on problem specific interventions and outcomes for people with advanced dementia

This dissertation carried out a systematic review of the research literature on nursing home residents with dementia. It also described the problems and interventions observed during a research study on advanced illness care teams (AICTs) that strived to improve the well-being of this target population. This section will summarize what was learned in carrying out the literature review and the descriptive study. The limitations inherent in the descriptive study will be explicated and suggestions for improving future research in this area will be outlined.

In evaluating all of the literature review studies, there is evidence that interventions can improve the well-being of nursing home residents with dementia. Analgesic medications are commonly used to treat pain but standard dosing practices are often ineffective especially for residents with other chronic conditions (Buffum et al., 2004; Chibnall, 2005). Opioid medications are also used to treat pain but are only effective in reducing agitation in residents over 85 (Manfredi et al., 2003). Training and educational interventions can be helpful to staff and families in responding to affective and behavioral distress (McCallion et al., 1999; Proctor et al., 1999; Teri et al., 2005; Robison et al., 2007). Person-centered, empathic approaches to care have also been successful in ameliorating depression and reducing problem behaviors (Toseland et al., 1997; Sloane et al., 2004; van Weert et al., 2005; Deponte & Missan, 2007). Exercise and movement activities have been effective in engaging residents, slowing cognitive decline, and decreasing agitation (Heyn, 2003; Stevens & Killeen, 2006; Rolland et al., 2007).
There are many other studies (summarized in the chapter 2 literature review) that have reported positive findings but the range and variety of interventions, not to mention the use of different outcome measures, make it difficult to draw meaningful comparisons between them. For example, validation therapy (Toseland et al., 1997; Deponte & Missan, 2007), sensorial reminiscence (Deponte & Missan, 2007), person-centered (van Weert et al., 2005), and a dementia-specific staff training (Teri et al., 2005) all significantly reduced behavior problems and/or distress. Similarly, music therapy (Svansdottir & Snaedal, 2006), individualized musical preferences (Gerdner, 2000), and familiar music with movement in a group (Sung et al., 2006) all significantly reduced agitation. These findings are promising and need to be replicated. There also needs to be more clarity about what makes an intervention effective. There were clearly differences in the active intervention elements and how these elements were implemented in the various studies. The three musical interventions that reduced agitation support the potential of music as an effective therapeutic but the three studies are so different in other respects it is likely that other elements in the intervention contributed to, or caused, the reduction in agitation. It is also worth noting that there were at least ten different behavioral measures used in the aforementioned studies These differences, along with the large number of interventions that have been evaluated in the literature, make it difficult to compare studies and establish the effectiveness of a given approach.

This difficulty in identifying the most effective interventions is compounded further by the apparent effectiveness of placebo conditions. For example, in a randomized controlled trial of a reminiscence approach to promote the well-being of residents, the reminiscence intervention and an “attention and social contact” comparison
condition both significantly improved social engagement scores (Lai et al., 2003). In another study, a “time and attention” placebo was just as effective as reminiscence therapy in reducing apathy (Politis et al., 2004). In addition to this, the time and attention condition in this study was significantly more effective than the treatment condition (reminiscence therapy) in raising the quality of life scores in nursing home residents with dementia. Although these findings may appear to ‘muddy the water’, they show that regular social contact, including social activities, can significantly enhance the well-being of residents.

In respect to the descriptive study that was part of this dissertation, five objectives were outlined as a way to describe the problems and interventions that emerged in the AICT study. This included the evaluation of a six-dimensional assessment framework to categorize the problems identified during the AICT study (Objectives 1, 2, & 3). In carrying out this evaluation, it was hoped that the problems that emerged in the AICT study would help to define an assessment framework that could be used by social workers, as well as other allied health professionals, in working with nursing home residents with dementia. The process of categorizing and counting the problems observed in the field, followed by a reliability study, provided meager support for a six-dimensional assessment framework.

The analysis of the AICT problems and interventions did confirm that pain and agitation were the most common problems in the study population. This finding paralleled the literature review in identifying pain and agitation as the most prevalent symptoms in nursing home residents with dementia. Pain and agitation were always categorized as physical/medical and behavioral problems, respectively. The prevalence
of pain and agitation supported the usefulness of the physical/medical and behavioral
domains in the aforementioned assessment framework. Although pain and agitation were
the most prevalent symptoms in the population, they were by no means universal. One
third of the problems were related to pain and just under a third of the problems were
related to agitation. This was an important finding that quantified the prevalence of pain
and agitation in the population.

Depression was the third most common problem and it was observed in a quarter
of the residents. Depression was always categorized as a psychological or psychosocial
problem and comprised over 90% of the problems in these two categories. It was
believed that problems with anxiety, delusions, and thought disorders would also be
found in the psychological and psychosocial categories but these symptoms were rarely
observed in the study population. The overlap in the psychological and psychosocial
categories suggested that a single psychosocial domain could adequately capture all of
the problems in these two categories. It is also worth noting that through this
categorizing of problems, it was learned that the prevalence of depression was much
greater than other psychological symptoms of dementia, at least in this particular sample
of nursing home residents.

The prevalence of pain, behavior, and, to a lesser extent, depression resulted in a
three-dimensional assessment framework (physical/medical, behavioral, and
psychosocial). These three dimensions captured 80% of all the problems documented on
the care plan review forms and could easily subsume the remaining problems that were
assigned to the family and meaningful activities categories used in the original six-
dimensional model. The resulting three-dimensional framework is similar to the
biopsychosocial assessment traditionally used by social workers. The addition of a
discrete behavioral domain to the assessment framework reflects the prevalence of
agitation (always categorized as a behavioral problem) in this population.

The identification and classification of interventions (Objective 4) used in the
AICT revealed that, on average, just over two interventions were developed for each
identified problem. The mix of interventions was individualized for each resident and,
although medications were used extensively, nonpharmacological interventions
outnumbered pharmacological interventions almost two-to-one. Nonpharmacological
interventions were used even more extensively in treating behavior problems,
outnumbering pharmacological interventions three-to-one. This demonstrates the
reluctance, at least in the two participating facilities, to use medications as chemical
restraints in managing unruly behavior. Pharmacological interventions were used
extensively in treating medical/physical and psychological problems. In these two
categories, pharmacological interventions were used about twice as much as
nonpharmacological interventions.

The effectiveness of the interventions (Objective 5) as rated by charge/supervising
nurses during a posttest interview may have reflected the generally better health of
residents who were able to participate in the AICT study. The favorable ratings for the
effectiveness of the interventions might have also been influenced by a social desirability
factor as almost 80% of the identified problems were “a little better”, “moderately
better”, or “a lot better” following the eight-week intervention period. The highest mean
change rating was given to psychosocial problems which also had the highest average of
interventions per problem. The lowest change rating was given to meaningful activities where spiritual issues were noted in just nine of the identified problems.

In reviewing the findings from the five objectives of this dissertation, there are several limitations in respect to what it contributes to the base of social work knowledge. First, it is a study that falls on the exploratory and descriptive end of the knowledge-building continuum. This continuum has commonly been described as having exploratory, descriptive, and explanatory purposes (Neuman, 2007; Yegidis & Weinbach, 2006). The explanatory end of the continuum is “probably the most esteemed function of research” in that it explains and predicts (Fortune & Reid, 1999, p. 75). The AICT study that provided the basis for this dissertation had an explanatory purpose that included well developed hypotheses, random assignment of subjects to treatment and control conditions, clear specification and introduction of the intervention (independent variable) and standardized measures at pretest and posttest to capture any change in the variables of interest (dependent variables).

This dissertation had exploratory and descriptive purposes which typically ask ‘what’, ‘how’, and ‘who’ questions (Neuman, 2007; Grinnell, 200 ). Many of the ‘who’ questions are answered in the demographic tables which showed that most of the residents were female, Catholic, and Caucasian. The MMSE and GDS scores confirmed that almost all of the residents participating in the study had severe cognitive impairment. Some of the ‘what’ questions posed by this dissertation included “What problems were identified during the AICT study” and “What interventions were developed in response to these problems?” A couple of ‘how’ questions included “How reliable were the six categories in the assessment framework?” and “How effective were the interventions
developed for the identified problems?” These are questions on the scientific road to causation but, by themselves, cannot explain why something happened or predict the effect of an intervention.

Exploratory and descriptive studies are generally an effort to understand phenomena and begin to formulate research questions and hypotheses (Neuman, 2007). The exploratory orientation of this dissertation can be seen in the one-group posttest only evaluation of the interventions. The use of a one-group posttest only research design is the most basic research design and this approach is generally associated with exploratory studies (Yegidis & Weinbach, 2007). This was a practical way to evaluate the effectiveness of individualized interventions from the perspective of nursing staff that were providing care to all of the residents participating in the AICT. However, the lack of a comparison or control group, pretest, standardized measures, and random assignment to treatment/control conditions are inherent weaknesses in this type of research design. The effectiveness ratings were also compromised by the direct involvement of the raters in the development and, in some cases, the implementation of the interventions.

To advance the social work knowledge base, future research will need have an explanatory purpose with clear, specific research question or hypothesis. Such a question could be “Is treatment that combines individual cognitive therapy and antidepressant medication more effective than antidepressant medication alone in reducing depressive symptoms in nursing home residents with mild to moderate dementia?” To answer this question, a study population of nursing home residents with mild to moderate dementia who are experiencing depressive symptoms would need to be identified. Reliable, standardized measures such as the Mini-Mental State Exam and Global Deterioration
Scale could be used to ensure that only residents with mild to moderate dementia are included in the sample frame. To ensure that all of the participants have depressive symptoms, the care plans of each participating resident would need to reference at least one depressive symptom and prescribe antidepressant medication. The pool of participating residents would then be randomly assigned to treatment or control conditions. Each participant’s depressive symptoms would be measured using a reliable, validated depression scale such as the Cornell Scale for Depression in Dementia or the Geriatric Depression Scale (Brink et al., 1982) prior to (pretest) and following (posttest) the period of intervention. The elements of the intervention need to be clearly outlined including the personnel responsible for its implementation and specification of the frequency and duration of the intervention. Close monitoring of the intervention should include fidelity checks to ensure quality and consistency in implementation. None of the participating residents should be receiving regular, ongoing counseling or therapy from nursing, pastoral, social work, or other staff since this is an active element in the treatment condition. Finally, the appropriate statistical analyses should be used to compare differences between the treatment and control groups in respect to changes on the outcome measures as well as demographic characteristics. An independent samples T-test could be used in this analysis or, if another treatment or placebo condition was added, a one-way analysis of variance would be a suitable statistical test.

5.6 Social work and research in nursing homes

There are many challenges to carrying out well-controlled research in the nursing home setting. This difficulty has been observed by Brodaty (2003) and his colleagues in their study on psychogeriatric teams and nursing home residents with dementia in
Australia. In this study, residents in both the control and treatment conditions experienced a reduction in the targeted symptoms. These reductions were attributed to a generalization of the intervention effects to residents in the control condition. This is similar to the AICT study that provided the basis for this dissertation. In the AICT study, residents in both treatment and control conditions showed improvement on pain and agitation measures. The generalization of treatment effects probably occurred, at least in part, during the preliminary and active phases of the intervention. During these phases, residents and their families began engaging with staff and researchers through informational meetings, the consent process, and during the orientation to the research project. This worked well for residents assigned to the AICT condition because the intervention period began immediately following these preliminary activities. However, for residents assigned to UC, these preliminary activities created opportunities for contamination.

In spite of the challenges in carrying out rigorous, empirically sound research in nursing home settings, there is a growing need to identify the conditions and best practices that improve the comfort, care, and well-being of nursing home residents with advanced dementia. Multidisciplinary teams are instrumental in planning the care for residents and, yet, there has been very little research on how to improve the effectiveness of these teams. There has also been very little research on the unique contribution that social workers make to care plans and to the team approach that is used in most nursing homes. In a recent article that examined the evidence base for social workers in long-term care settings (Simons, Shepherd, & Munn, 2008), the authors found that research does support the effectiveness of social work services in providing case management and
interdisciplinary geriatric interventions in community-based practice. However, in nursing homes and hospitals, there is little evidence to support the unique contribution of social workers in the planning and provision of care.

In reflecting on this disappointing finding, one might ask “Do social workers make a unique contribution in providing care to residents in nursing homes?” In the AICT study, MSW level social workers participated as members of care planning teams and were instrumental in the development of care plans. Social workers provided individual therapy to residents with depressive symptoms and had the primary responsibility for engaging family members in AICT meetings. Social workers ensured that family members who did not attend AICT meetings were informed about the care plans that were developed in these meetings. This family liaison role is typical of what social workers do in nursing homes. In this role, social workers learn about a resident’s life course including strengths, needs, and preferences from the family’s perspective. By understanding the family’s perspective and the resident’s life context, the social worker can help create a care plan that is, ideally, more comforting and responsive to the resident. This comprehensive, holistic understanding of the person in their life context is central to social work practice and it is a unique contribution that social workers make in providing care to residents in nursing homes.

Social workers undoubtedly have an important role to play when it comes to improving the quality of care and quality of life for nursing home residents with dementia. The National Association of Social Workers (NASW) has identified the provision of quality psychosocial care, which includes the social, mental health, and emotional needs of individuals, as a primary goal of nursing home social work. The
importance of social work services has also been established through federal legislation (1987 Nursing Home Reform Act) mandating social work services in nursing homes that receive federal funds.

Although social workers often play a central role in the provision of quality psychosocial care to nursing home residents, it is not known if this is the primary or most common role that they play. As noted at the end of chapter 2, there have been few empirical studies of what social workers actually do in long-term care settings (Koren & Doron, 2008). This lack of information has been compounded by the fact that psychosocial care and other typical social work activities have been carried out in most nursing homes by non-social work staff. Even though federal mandates require social work services in homes receiving federal funds, 70% of nursing homes in the United States have 120 (or fewer) beds, and these smaller homes are exempt from these federal mandates (Bern-Klug, 2008). As a result, there is much to learn about what duties and roles are actually carried out by social work professionals working in long-term care.

A recently completed report prepared by the United States Department of Health and Human Services confirms that social workers play a vital role in long-term care services for older adults (U.S. Department of Health and Human Services, 2006). This report projects an increasing need for professional social workers in the provision of long-term care services to older adults in future years. In responding to this increasing need for social workers, the profession needs to have a better understanding of the most common, as well as the most important, services provided by social workers in long-term care. The challenge for social work is to further strengthen the credibility of their unique
practice perspective through research that corroborates the value and the effectiveness of social work services in long-term care.
References


Omnibus Budget Reconciliation Act of 1987, Public Law 100-203, Title IV, Section 4201 (a) (3), 101 STAT. 1330-160 to 1330-165, 42 U.S.C. § 1395i-3 (December 22, 1987).


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