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## The Effects of an Experiential Learning and Mentorship Program Pairing Medical Students and Persons with Cognitive Impairment: A Qualitative Content Analysis

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LOYOLA UNIVERSITY CHICAGO

THE EFFECTS OF AN EXPERIENTIAL LEARNING AND MENTORSHIP  
PROGRAM PAIRING MEDICAL STUDENTS AND PERSONS WITH COGNITIVE  
IMPAIRMENT: A QUALITATIVE CONTENT ANALYSIS

A DISSERTATION SUBMITTED TO  
THE FACULTY OF THE GRADUATE SCHOOL  
IN CANDIDACY FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY

DARBY J. MORHARDT

CHICAGO, IL

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As you go into a (mentoring relationship) you must remember that you are not the giver and the other a receiver, but that this is about RECIPROCITY, where if you cannot grow and learn from each other, this relationship will not prosper!

– Dr. Johnetta Cole, President, Spelman College

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## ABSTRACT

The United States population is aging rapidly and with it comes a tremendous rise in the number of people with dementia. In the future, as now, physicians and other health care professionals will likely provide the majority of health care for older people and those with dementia. The non-geriatric trained workforce must have the attitudes, knowledge and skills needed to provide high quality care for this aging and increasingly cognitively impaired population. There is evidence that prevailing stigma regarding older adults can be modified with experiential opportunities early in students' careers. Few of these programs are aimed at persons with dementia. The purpose of this study was to obtain an understanding of the impact of an experiential learning and mentorship program, the Buddy Program, with persons diagnosed with early stage dementia on first year medical students. This study is a qualitative content analysis of medical students' narrative reflections following their interaction and activity with a person with dementia over the course of an academic year. The study utilizes the theoretical frameworks of Gordon W. Allport's (1954) contact hypothesis, theories of personhood, and the social constructionist view of the self within an interpretivist/constructivist paradigm. The results of this study yielded insights into what the students experienced over the course of the year. Themes that emerged in their reflections of this experience included (a) seeing the person with dementia as a mentor; (b) expressing a range of feelings regarding the relationship from discomfort to enjoyment, friendship and increasing comfort over time;

(c) demonstrating perceptions of mood and development of empathy toward the person with dementia; (d) recognizing and learning the various symptoms manifested in persons with dementia; (e) developing an awareness of their preconceptions and changing attitudes, along with their own emotional response to the experience; and (f) understanding the family caregivers' experience through interaction. It was ultimately concluded that this experiential program served to influence first-year medical students' understanding of persons with dementia, providing them with a more holistic view of the person and family and challenging and altering students' preconceptions of dementia and what it is like to live with it. Implications for social workers are discussed along with the study limitations and next steps for future research.

## CHAPTER ONE

### INTRODUCTION TO THE STUDY

This dissertation reports the findings from a study instituted in an Alzheimer's Disease Center funded by the National Institute on Aging to investigate the effects of the Buddy Program, a program providing first year medical students with first-hand experience over a protracted period of time with patients in the early stages of dementia. The following establishes the rationale for the study and methods.

#### **Significance and Background**

There is a growing concern over who will provide for the care of our aging population. Those 65 and over represent 13.3% or 41.4 million of the U.S. population (an 18% increase since 2000) and are expected to grow to 21% of the population by 2040. Projections indicate that they will more than double to 92 million in 2060 (Administration on Aging, 2012). The greatest increase in the U.S. population will be among those age 85 and older. This cohort is at the highest risk for dementia, particularly dementia caused by Alzheimer's disease.

This increasing aging demographic of older adults will contribute to a growing demand for health care professionals trained and committed to working with this patient population (American Geriatrics Society, 2013; Institute of Medicine, 2008). However, in the future, as now, physicians and other health care professionals who are not geriatricians will likely provide the majority of health care for older people and those

with dementia (Reuben et al., 1993). The non-geriatrician workforce must have the attitudes, knowledge, and skills needed to provide high quality care for an aging population.

### **What is Dementia?**

Dementia is a condition of the mind caused by a disease of the brain. It is not a specific disease. It is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. Dementia is the insidious onset and gradually progressive loss of cognitive functioning – thinking, remembering, and reasoning – and behavioral abilities to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living (National Institute on Aging, 2013). Alzheimer's disease (AD) is the most common cause of dementia among older people over the age of 65.

Dementia is estimated to affect approximately half of those over age 85 (Brookmeyer et al., 2011). Over the last 25 years, health and social service professionals, researchers, policy makers, and society as a whole have become more aware of dementia, particularly Alzheimer's disease. According to the National Institute on Aging (2011), as many as 5.1 million Americans have Alzheimer's disease as a cause of their dementia and others have related neurodegenerative diseases. The Alzheimer's Association reports Alzheimer's as the sixth-leading cause of death in the country (Alzheimer's Association, 2013). Based on mortality data from 2000-2008, death rates have declined for most

major diseases while deaths from Alzheimer's disease have risen 66% during the same period (Alzheimer's Association, 2013). As a consequence of increased longevity and expansion of the older adult population, it is projected that by 2050, AD will affect 13.2 to 16 million United States citizens (Brookmeyer et al., 2011).

Due to the projections, dementia poses physical and emotional challenges not only for those affected, but also for families and other caregivers. Less than one in four people with dementia receive a formal diagnosis (Boise, Neal, & Kaye, 2005; Callahan, Hendrie, & Tierney, 1995; Ganguli et al., 2004). Without a diagnosis, few people receive appropriate care, treatment and support.

Alzheimer's disease has also moved to the forefront of our legislative concerns. On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA) (Public Law 111-375) passing unanimously in both the Senate and the House of Representatives. NAPA required the Secretary of the U.S. Department of Health and Human Services (HHS) to (1) create and maintain an integrated national plan to overcome AD; (2) ensure the coordination of AD research and services across all federal agencies; (3) accelerate treatment development to prevent, halt or reverse AD; (4) improve early diagnosis, care coordination and treatment of AD; (5) improve outcomes for higher risk ethnic and racial minority populations; and (6) coordinate internationally to fight AD on a global scale (National Alzheimer's Project Act, 2011).

Given the described demographic shifts that will occur over the next 30 years, the success of NAPA is of great importance to people with AD and their family members, public policy makers, and health and social service providers. One of the five concrete



goals to achieve the vision of NAPA is to enhance care quality and efficiency by building a workforce with the skills to provide high-quality care for people with Alzheimer's disease (U.S. Department of Health and Human Services, 2013). This includes educating health care providers such as primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct-care workers like home health aides and certified nursing assistants, who provide care at home or in assisted living or nursing homes. NAPA has begun a comprehensive effort to address this goal by educating health care providers about dementia through the Health Resources and Services Administration's Geriatric Education Centers; encouraging providers to pursue careers in geriatric specialties through the enhancement of the 'Comprehensive Geriatric Education Program as mandated by the Affordable Care Act, supporting training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists, and supporting the career development of geriatric specialists in academia through the "Geriatric Academic Career Awards Program" (U.S. Department of Health and Human Services, 2013).

### **Preparing Health Care Professionals**

However, long before NAPA, experts in health policy and practice called for more comprehensive education for healthcare professionals in the area of dementia and aging to meet the needs of the growing number of older adults in the United States and a significantly larger workforce of nearly all health specialties to meet the needs of older

adults (over the age of 65) by the year 2030 (American Geriatrics Society, 2013; Bragg & Hansen, 2010; Institute of Medicine, 2008; Whitaker, Weismiller & Clark, 2006). The Alliance for Aging (2013) states that the number of health care professionals that are specializing in geriatric care is declining. Research estimates that 36,000 geriatricians will be needed to care for the growing number of elderly citizens and approximately 17,000 are needed now. However, as of today, there are fewer than 8,000 certified geriatricians in the United States and the number is expected to fall to 6,000 due to retirement and declines in re-certification. Furthermore, less than 10% of medical schools require separate coursework or rotation in geriatrics, and less than 3% of medical school graduates take elective courses in this specialization (Alliance for Aging Research, 2013). There are currently less than 1600 geriatric psychiatrists to care for the aging population in the United States (American Geriatrics Society, 2013). Furthermore, less than 1% of nurses, pharmacists, and physician assistants; and about 2.6% of advanced practice registered nurses are certified in geriatrics (Institute of Medicine, 2008). Besdine et al. (2005) cautioned that “the combination of a burgeoning number of older persons and an inadequately prepared, poorly organized physician workforce is a recipe for expensive, fragmented health care that does not meet the needs of our older population” (p. S253).

A similar push to increase the knowledge base of social workers has been underway for the past 10 years. In 2006, Hooyman, Council for Social Work Education, outlined the shortage of bachelor’s and master’s prepared social workers with gerontological competencies to provide effective psychosocial care for older adults and their families, estimating that approximately 55,000 social workers are currently needed

in long-term care. By 2050, this number will nearly double to approximately 109,000. Although nearly 75% of licensed social workers work with older adults in some capacity, many have not received training or education in gerontology. In 2009-2010, only 2.8% of BSW graduates and 6.7% of MSW graduates completed a specialization in aging, an average of 5% across all social work graduates (Council for Social Work Education, 2011). Three hundred fifty-eight social workers were credentialed in gerontology according to the National Association of Social Workers, 2010.

### **Attitudes toward Aging and Dementia**

One reason for the dilemma facing the public health crisis of aging-related dementia is that healthcare professionals in general, and physicians in particular, tend to have a negative attitude toward older patients, limited knowledge, and limited interest in pursuing geriatric or dementia care (Berenbaum, 2000; Brooks, 1993; Coccaro & Miles, 1984; Deary, Smith, Mitchell, & MacLennan, 1993; Fitzgerald, Wray, Halter, Williams & Supiano, 2003; Hobbs, Dean, Higgs, & Adamson, 2006; Jansen & Morse, 2004; Kaempfer, Wellman, & Himburg, 2002; Lee, Reuben & Ferrell, 2005; Lutsky, 1980; McIntosh, Swanson, Power, & Rae, 1999). Studies have found that medical, nursing, social work, and physical therapy students rank older patients as the least desirable to work with (Carmel, Cwikel, & Galinsky, 1992; Taylor & Tovin, 2000). Several authors attribute this lack of interest to the pervasiveness of negative attitudes toward older adults among younger adults (Burg et al., 2001; Damron-Rodriguez, Kramer, & Gallagher-Thompson, 1998; Gorelik, Damron-Rodriguez, Funderburk, & Solomon, 2000; Hawkins, 1996; Kaempfer et al., 2002; Moriello, Smey, Pescatello & Murphy, 2005; Mosher-

Ashley & Ball, 1999). Younger individuals have also been found to hold misconceptions of the older adult as frail, pessimistic, intolerant and complaining (Moriello et al., 2005) and as physically impaired and dependent on others (Mosher-Ashley & Ball, 1999).

There is also an emotional cost of working with older people due to countertransference fears of aging, dependency and death and working with those who look like one's grandparents. Most of our society also erroneously assumes that losing mental capacity to the point of incapacity is inevitable with aging (Thornton, 2002).

### **Education and Training in Aging and Dementia**

Some institutions have improved future medical professionals' general knowledge and attitudes by developing educational programs that introduce medical students to healthy older adults (Bernard, McAuley, Belzer & Neil, 2003; Shue, McNeley & Arnold, 2005). Although these programs have had a positive effect, some require a significant time commitment on the part of the student and faculty (Deary et al., 1993; Intrieri, Kelley, Brown & Castilla, 1993). Results of research on medical student knowledge and attitudes regarding older adults reveal that: (1) learning about aging appears to result in positive attitudinal change (Deary et al., 1993; Edward & Aldous, 1996; Tullo, Spencer & Allan, 2010); (2) a combination of classroom and experiential activities is particularly effective (National Institute on Aging, 2006; O'Hanlon & Brookover, 2002); and (3) early exposure is best (Wilkinson, Gower, & Sainsbury, 2002).

However, while there is evidence that teaching interventions in geriatrics in general can improve knowledge, skills and attitudes of medical students, few of these interventions include specific learning outcomes relevant to dementia and the majority do

not address the significant lack of trained healthcare professionals who simultaneously understand the strengths, limitations, and needs of persons with memory impairment and dementia. A survey of more than 500 hospital and community physicians in the USA cited better understanding of dementia as the most commonly identified learning need in geriatric medicine (Robinson, Barry, Renick, Bergen, & Stratos, 2001).

The provision of competent care for patients with dementia is a challenge for medical professionals, both in the hospital and in the community (Doyle, 2009; Pachana, 2010). Although knowledge about the assessment and management of Alzheimer's disease and related dementias has increased and has been widely disseminated, many healthcare professionals remain uninformed (Barrett, Haley, Harrell, & Powers, 1997; Boise et al., 2004; Meuser, Boise & Morris, 2004). A general consensus of the Undergraduate Education Subcommittee (UES) of the American Academy of Neurology resulted in a stated need for a more standardized effectiveness-proven medical student neurology curriculum (Isaacson, Safdieh, & Ochner, 2011). As a result, the *Continuum for Medical Students: Dementia* was developed and tested in a randomized controlled trial demonstrating that the specialized curriculum improves medical knowledge of dementia over the standard curriculum alone. Physicians are in a unique position to contribute significantly to the quality of healthcare delivered. For the first time in medical policy making, cognitive health is being included in the Medicare prescription for the wellness visit. In order to improve the quality of health care delivered to older individuals with dementia and persons of any age with dementia, attitudes, knowledge and beliefs regarding older adults, aging and dementia should be further investigated.

### **The Biopsychosocial Perspective**

Central to social work is the notion that individuals must be understood in terms of social context; i.e., person: environment (Gitterman & Germain, 2008). Social work is a profession that seeks to change and improve the lives of individuals and society and the relationship between them. This perspective has its roots in general systems theory (Von Bertalanffy, 1972) because it views a person's health status as reflecting the interdependency of physical, psychological, and social environmental systems. General systems theory holds that all levels of organization in nature are linked so that change in one affects change in the others (Engel, 1977).

Engel's (1977) seminal article on the biopsychosocial perspective in medicine greatly impacted undergraduate medical education. He focused on 'the system' and how it can make people sick as well as better. Implicit in the psychosocial model is the recognition that the biochemical problem, life experience, and the current social situation all matter in the presentation of illness and influence what the physician sees in the consulting room.

Virtually every medical school in the United States includes a biopsychosocial curriculum, sharing common values with social work education; i.e., the acquisition of specific clinical knowledge, skills, and attitudes that integrates an understanding of the biopsychosocial determinants of health and disease along the continuum of diagnosis, treatment, and prevention (Frankel, Quill, & McDaniel, 2003).

Northwestern University Feinberg School of Medicine (NUFSM, 2013) launched a new curriculum and competency-based education framework in Fall 2012. NUFSM defines the curricular expectations and goals as:

### **1. Patient-Centered Medical Care**

Proficiency in the clinical skills and knowledge necessary to enter postgraduate medical education. Skills, knowledge, and clinical evidence with attention to patients' perspectives, needs, values, and comfort.

### **2. Effective Communication and Interpersonal Skills**

Communication (both verbal and non-verbal) and interpersonal skills and strategies that result in respectful, compassionate, and effective information exchange and decision making with patients, families, members of the healthcare team, and other colleagues.

### **3. Medical Knowledge and Scholarship**

Knowledge of the scientific basis of medicine, the ability to apply knowledge to patient care and contribute to scholarship in medicine through research or teaching.

### **4. System Awareness and Team-Based Care**

Awareness of the overall healthcare delivery system as well as the system of care in each of their clinical settings, and demonstrate the ability to work as an effective member of the healthcare team.

### **5. Personal Awareness and Self-Care**

The capacity to self-reflect on their acculturation to medicine, to assess the impact of medical school experiences on evolving personal and professional values, and to tend to one's own physical and mental health.

### **6. Community Engagement and Service**

Knowledge of community factors that influence individual, community and public health, and perspective and experience through service-learning activities within local or global community settings.

## **7. Continuous Learning and Quality Improvement**

The ability to accurately assess and improve classroom and clinical performance, as well as acquire, appraise, and apply scientific evidence to classroom activities and patient care.

## **8. Professional Behavior and Moral Reasoning**

A commitment to professional responsibilities and behavior as well as the ability to understand, reflect upon, and integrate ethical and moral dimensions of healthcare.

These competencies reflect a biopsychosocial perspective, particularly in their awareness of and focus on patient-centered care, the need for effective communication and interpersonal skills, the system awareness, and team-based care and community engagement and service. In terms of community engagement and service, medical students are expected to

demonstrate knowledge about behavioral, socioeconomic and cultural dynamics that can affect individual, community health and global health, assess challenges to providing high quality healthcare for members of vulnerable groups and articulate the role of physicians in working to eliminate barriers, advocate for individual patients and communities with limited access to quality healthcare, and promote the health and welfare of a community group by eliciting needs and assets and collaborating with community partners to deliver sustainable, quality service. (NUFSM, 2013).

In terms of meeting the competency of systems awareness and team-based care, students are to

demonstrate a clear understanding of healthcare team goals, primary roles of team members and work effectively to help the team achieve its goals and demonstrate skills in handing off care from one clinical team member to another during periods of transition within and between healthcare settings. (NUFSM, 2013)



### **Significance for Social Work Education**

Similarly, the biopsychosocial perspective is at the core of social work practice in the health care setting. Social workers value and are concerned with the interaction of physical, psychological, and social conditions of the patient, both as causes and effects (Cowles, 2003). Clinically, medicine and social work respect and honor patient/client wishes. Both have an educational curriculum that is aligned with evolving societal needs, practice patterns, and scientific developments. Both are concerned with professional growth and development and value patient safety, teamwork, and collaboration.

Operating from a biopsychosocial framework requires the integration of an interdisciplinary team to provide better care and address the patients' needs at the biopsychosocial levels (Gatchel & Oordt, 2003). Integrated interdisciplinary teams often comprise physicians, nurses, social workers and other specialties to address all three aspects of the biopsychosocial framework. The team approach to care provides an opportunity for the melding of both the biological determinants of health and disease with the psychosocial aspects. However, training in these disciplines (medical, nursing, social work) often does not include exposure to these other disciplines. It has been argued that to be effective team members, students in all health professions should work with colleagues from other disciplines at an early stage of role development (Giardino, Giardino, & Siegler, 1994).

### **Medical Humanism**

Related to the biopsychosocial model of care is the medical humanism of William Osler (Ghaemi, 2009):

Osler argued the physician's role was to treat disease in the body (biomedical reductionism) while attending to the human being, the person, who has the disease. Osler applied the medical model in this way: Where disease is present, one treats the body; where disease is ameliorable but not curable, one still treats with attention to risks; and where no disease exists one attends to the human being as a person. (p. 4)

Whether viewed from a biopsychosocial model or through the lens of medical humanism, there is complexity to individuals who live with illness. There is more to a person than their illness and it is this point the buddy program strives to instill in medical students.

### **Borderlands – The Challenge of Integrated Care**

Unfortunately, the integration of biopsychosocial care is very difficult to put into practice and challenges include a variety of historical, cultural, and financial barriers. Hinton, Flores, Franz, Hernandez, and Mitteness (2006) described the relevance of the concept of borderlands in examining the interface of dementia and primary care settings, particularly behavior changes that create a struggle among families and clinicians to clarify, understand and negotiate care in a medical system that lacks adequate training in geriatrics and mental health, coupled with short office visits and the lack of continuity of formal services. The concept of 'borderlands' was originally defined by Anzaldua (1987) as "situations physically present whenever two or more cultures edge each other, where people of different races occupy the same territory, where under, lower, middle, and upper classes touch, where the space between two individuals shrinks with intimacy" (p. 19). Her writing, which derives from her own experience growing up as a Latina woman on the Texas-Mexico border, highlights the psychological meaning of living between two cultures. Among other things, this situation requires of those who live in it a tolerance of the ambiguity that results from contact with multiple, sometimes contradictory cultural

frames. Similarly, there are two cultural frames (medical and psychosocial) present in primary care for persons with dementia. Hinton et al. (2006) suggest that, “within these borderlands, the influence of ethnic/cultural and gender differences and the power inherent in the role of the physician, caregiver, and health system can be acknowledged, recognized, and renegotiated to create sites for collaborative partnership in healing and support” (p. 61).

Liebing (2008) examines the ‘entangled matter’ of those who “accuse biomedical reasoning of undermining personhood...forming notions of what one could describe as a ‘personhood movement’ with the “biologization of dementia” (p. 193). She cautions this kind of dualistic thinking – “personhood versus biomedicine,” and suggests we look at it as “contested space, created by many voices, tensions, power plays with many paths still open to conquer and to explore” (p. 190).

In summary, the changing epidemiology of the aging population means that the majority of doctors, in a range of non-specialist roles, are likely to spend more time caring for patients with dementia. The provision of competent care remains a challenge for medical professionals and there is concern that few possess the knowledge, attitudes or skills to provide adequate care for persons with dementia. Doctors themselves appear to recognize this due to their identification of a better understanding of dementia as a top learning need in geriatric medicine (Robinson et al., 2001). While a foundation for dementia education needs to be established for medical students within the undergraduate curriculum before being carried through and translated into competent care, this

researcher seeks to understand how an early experience in their medical curriculum affects their knowledge and attitudes.

### **Purpose and Research Question**

The purpose of this study is to dissect and characterize the experience of first year medical students who take part in an experiential learning and mentorship program.

The research question is: What is the impact of an experiential learning and mentorship program with persons diagnosed with early stage dementia on first year medical students?

## CHAPTER TWO

### THE BUDDY PROGRAM: HISTORY AND FINDINGS

#### **Buddy Program History**

The Buddy Program was developed by this researcher at the Cognitive Neurology and Alzheimer's Disease Center (CNADC), Northwestern University Feinberg School of Medicine (NUFSM) in 1997 to provide an opportunity for first year medical students and persons diagnosed with early Alzheimer's disease and related disorders to participate in an experiential learning and mentorship program (Morhardt, 2006).

The program concept originated as a result of a physician who, after being diagnosed with AD, was faced with a loss of his life's work. Although no longer able to practice medicine, this long serving and productive physician believed he was still able to impart valuable experience and knowledge and 'mentor' a medical student. Simultaneously, it was thought the student might benefit not only from the physician's experience and perspective, but also receive a better understanding of the impact of cognitive decline on his life, at a stage when the affected individual does not 'look sick'. The idea was for the student and person with dementia to be 'buddies,' sharing experiences rather than being engaged in a clinical or hierarchical relationship. This became an opportunity for the persons with dementia to impart their experiences and knowledge to students many years their junior, reflecting the aspect of generativity that involves guiding future generations (Erickson, 1950).

Therefore, the Buddy Program is rooted in the value and belief that persons with early stage dementia, in whatever way their declining cognition is changing and modifying their functioning, have the continued capacity to make meaningful contributions to society and others. In essence, the buddy program is based on relationship, conversation, dialogue, and reciprocity. It is about empowerment of the person with dementia in a world where they are at risk of being marginalized and disempowered as they lose cognitive capacity. The person with AD receives companionship and social interaction and the opportunity to mentor; the student, the recipient of that mentoring, has an opportunity to have their image of persons with AD shifted and transformed through this mutual relationship. As a result, the role and title of ‘mentor’ was given to the person with dementia.

In the Buddy Program, students are paired with diagnosed individuals in the early stage of dementia. Early stage dementia is defined as mild to moderate impairment as a result of the illness. Individuals in this stage are capable of continued independent functioning in many areas. Symptoms usually include difficulty concentrating, decreased memory of recent events, difficulty managing finances, driving or traveling alone to new locations. They may have trouble completing complex tasks efficiently or accurately and may have differing levels of insight into their symptoms. People in this stage are still able to manage their own personal care independently and are able to engage in a give-and-take dialogue (Alzheimer’s Association, 2013).

The ‘buddies’ plan a year of regular meetings around mutually satisfying activities, such as visiting museums, attending concerts, sharing a meal or simply going

for a walk. These activities are identified in a pre-program event where the students and their ‘buddies’ meet in an informal atmosphere and share information about themselves with one another. Matching is based on compatibility of interests, logistical concerns and demographic preferences. The program directors meet with each student individually to facilitate the best match possible.

### **Buddy Program Goals**

The goals of the buddy program are to:

- 1) Educate medical students about Alzheimer’s and related conditions by
  - increasing their knowledge base about dementia,
  - heightening their awareness of skills and strengths that remain in people with cognitive impairment, especially in earlier stages of illness when they appear normal but may have significant cognitive limitations
  - providing opportunities to witness firsthand how someone with early stage Alzheimer’s disease and related conditions responds to his or her own changing abilities, and
  - familiarizing students with issues of the daily care and support of persons with dementia and their families and the most effective ways of communicating with them.
- 2) Introduce students to research and practice opportunities in fields related to aging and memory impairments,
- 3) Provide persons living with dementia an opportunity to serve as a mentor to a future doctor, regardless of their own area of expertise, and
- 4) Provide persons living with dementia an opportunity for life enrichment.  
(Morhardt & O’Hara, 2012)

### **Buddy Program Core Elements**

Students are recruited from the first year medical school class during Orientation Week, typically the third week of August. A program information luncheon is held for interested students and the program objectives and core elements are described (see Appendix A). These core elements are: (1) commitment to program participation for one academic year; (2) complete pre/post testing on dementia knowledge and attitudes; (3)

participate in three hours of orientation on dementia, the diagnosed person and family experience and communication skills; (4) attend the initial ‘match day’ program to meet their buddy/mentor; (5) engage in activity with the assigned mentor at least four hours a month; (6) complete and submit a written report following each activity; (7) participate in a monthly student group process meeting; (8) complete a reflection paper at the end of the year; (9) attend an end-of-the-year gathering of students, mentors, and their families; and (10) complete a program evaluation survey.

All interested students complete an application and undergo a 20-30 minute interview with the researcher and researcher’s colleague (a social worker who assists with the buddy program implementation). Medical students are selected based on their ability to commit to program requirements. A maximum of 12 to 13 students are accepted into the program per year.

Persons with dementia are recruited through the Clinical Core, a research registry of the Cognitive Neurology and Alzheimer’s Disease Center and also from the Neurobehavior and Memory Clinic of the Northwestern Medical Faculty Foundation. The director of the program, herself a clinician and researcher in these settings, knows all of the selected mentors well before pairing them with a student.

Inclusion criteria for persons with dementia include:

- A complete work-up resulting in a diagnosis of Alzheimer's disease or a related disorder;
- Acknowledgment of memory loss and some degree of recognition that it may come from Alzheimer's disease or a related disorder;
- Interest/willingness to be matched with a first year medical student;
- Commitment to meeting with a student for approximately 4 hours per month;
- Ability to verbally converse adequately;



- Free of functional impairments requiring assistance or supervision (i.e., assistance with toileting);
- Free of psychiatric disabilities that would negatively affect the ability to engage in a meaningful relationship with a student;
- Willingness to participate in end-of-the year focus groups and complete evaluation questionnaires.

### **Buddy Program: Preliminary Findings**

The Buddy Program matched 167 student and mentor (buddy) pairs between 1997-2013. Program evaluation included pre- and post-testing regarding students' dementia knowledge, post-program evaluation by the diagnosed person, family member, and medical student, a preliminary qualitative analysis of activity journals kept by the medical students (Morhardt & Iris, 2001) and a qualitative analysis of interviews held with a sample of mentors and their families after one academic year (Lord & Morhardt, 2005).

### **Initial Qualitative Analysis of Student Journals**

As outlined, each student was required to submit a journal detailing their activity and experience with their mentor as soon as possible following their meeting. An initial content thematic analysis (1997-2001) of students' journal data and program evaluations (N=42) revealed the following themes: (1) students' growth in dementia knowledge and comfort with mentor; (2) students' increased understanding of helpful communication skills; (3) students' recognition of their mentor's dependency upon them; (4) students' development of empathy and compassion for mentor; (5) students' recognition of helplessness and frustration; and (6) students' feelings of growth and development in their career (Morhardt & Iris, 2001). These initial themes coded by the researcher on the

first four program years, provide the foundation for the more rigorous evaluation conducted in the present study.

### **Qualitative Analysis of Mentor Experience**

Following the 2004-05 academic year a qualitative analysis of interviews with diagnosed persons and families assessed the program's impact on the person with dementia (Lord & Morhardt, 2005). In-person interviews were held with persons with dementia who had participated in the program year 2004-05 (N=8) and their family members (N=8). The interview included an exploration of the program's impact on the person with dementia, any benefits, and ways the program could be improved. Results revealed that the greatest program benefit was the opportunity for social interaction due to the person's increasingly restricted life. Mentors spoke of the positive impact of the student taking an interest in them and remarked about the benefits of spending time with young people.

The strengths of the student/mentor relationship varied. In the autobiography that one mentor wrote over the year, he included a section describing his relationship with his student buddy and the closeness he felt. On the other hand, another mentor reported that she and her student buddy only met twice during the entire year, implying a lack of connection. However overall, the buddies and their family caregivers expressed positive feelings about the program and that it was beneficial to all participants.

Another emerging theme was how much the individuals with dementia appreciated and found it beneficial to be able to discuss the disease with their buddy. They found that the student was an important source of information on the disease.

Caregivers also reported improvements in the mood of their family member with dementia after spending time with the students. In response to the question: “Has this program benefited their mood?,” one caregiver responded, “Oh, wow! You want to talk about a scale of one to ten. I mean, the buddy would call and he was maybe at six and then he would be up to ten... There was no question. It was dramatic...dramatic (Lord & Morhardt, 2005, cg#3).

In terms of benefits to the students, the person with dementia and the caregiver both indicated that the program provided important exposure to dementia. The person with dementia also expressed feeling responsibility for educating the student and for creating more sensitive physicians for the future. For example, one stated, “I feel somewhat responsible for helping them to do the right thing in terms of talking to people with Alzheimer’s...the people that enter into the fray are doing the right thing by the people who have the disease” (Lord & Morhardt, 2005, buddy#1).

Benefits to the caregiver varied. For caregivers who had more dependent spouses, they felt the program provided an important break and time off. It was less beneficial for caregivers with more independent spouses. On the other hand, the program provided social contact for caregivers who had more restricted social lives.

Another theme to emerge from these interviews was the students’ contributions to the mentor’s individuality and their sense of self; that is, the person they were before the disease. The program aided in the mentors’ maintenance of independence by allowing them to make decisions and to interact with their buddies on their own. One caregiver stated, “He likes the idea of making the decisions of what he and (his buddy) do. There’s

a loss of power here [with his disease]...But (his buddy) is his decision. It gets him a little power going..." (Lord & Morhardt, 2005, cg#2).

Suggestions for improvement included making sure that the student had the time and ability to commit to the program, taking care to better select and educate the students, making a good match by linking common interests and background, and increasing oversight of the buddy pairs.

Following this study, operational elements were modified and integrated into the program structure. For example, while initially all students who wanted to volunteer for the program were accepted, not everyone was able to fulfill the program requirements and some had difficulty interacting with their mentor. Simultaneously, not all mentors were able to engage in a reciprocal relationship with a medical student due to advanced disease or behavioral/psychiatric symptoms that understandably created anxiety in the students during their interactions. Therefore, as a result of the study by Lord and Morhardt (2005), interviews for both students and persons with dementia were implemented to the program structure prior to acceptance into the program. A list of inclusion and exclusion criteria was developed to aid in this process.

### **The Buddy Program – Publication and Replication**

In 2006, a manuscript was published on the 'Buddy Program', describing the program's feasibility and lessons learned (Morhardt, 2006). In 2007, the first program replication was developed by Boston University's (BU) Alzheimer's Disease Center in conjunction with their medical school. The program entitled PAIRS (Partnering in Alzheimer's Instruction Research Study) introduced a reflection paper at the end of the

program year in addition to a lengthier pre-post Alzheimer's Disease Knowledge Test. A quantitative and qualitative analysis of four years of pre/post knowledge tests and end-of-the-year reflection papers was published (Jefferson, Cantwell, Byerly, & Morhardt, 2012). Data was presented on four consecutive years of the PAIRS program. Results revealed a modest, but statistically significant improvement in dementia knowledge post-program ( $p < 0.001$ ). Using qualitative coding methods, 12 overarching themes emerged from the students' reflective essays, such as observing care partner burden, reporting a human side to Alzheimer's disease, reporting experiences from the program that will impact future clinical practice and obtaining a greater understanding of Alzheimer's disease.

Further program replications have occurred at Dartmouth College, Washington University and University of Bari-Italy. The University of Kansas and Albany Medical College are beginning their programs in Fall 2013. All replicating sites are using the Buddy Program Manual (Morhardt & O'Hara, 2012) (see Appendix B), which provides program design, recruitment criteria for students and diagnosed individuals, student orientation curriculum and template forms for data collection, including a Dementia Knowledge Test (Morhardt, 2006), activity journal template, program evaluations and a format for longitudinal follow-up. All sites have agreed to share outcome data and are collaborating on a dissemination of findings, through conference presentations (Morhardt et al., 2013), proposals for additional funding and manuscript preparation. Gathering outcome data from multiple centers strengthens the study and facilitates generalization of the results.

Although the studies reported about have begun to disseminate information about the buddy program, to date a rigorous qualitative analysis of the students' activity journal reports has not been attempted. While the reflection papers capture the students' retrospective conclusions of the program's impact on their beliefs, attitudes and knowledge, the activity journals capture immediate reflections following individual meetings with the person with dementia and student's beliefs, attitudes and knowledge over the course of the academic year. Thus, an analysis of these reflections with qualitative methods would provide a novel, as yet unexplored, source of information about the development of the student and mentor's relationship and the student's reflections of, attitudes toward and understanding of persons living with cognitive impairment over the course of a year.

## CHAPTER THREE

### REVIEW OF THE LITERATURE AND THEORETICAL FRAMEWORK

#### **Introduction**

The following is a review of the literature on education and training of medical students regarding aging and dementia, general societal and medical student attitudes towards older adults and persons with dementia and the experience of older persons' interactions with physicians in the health care system. This review is based on a search of several databases including Medline, CINAHL, PsychInfo, and PubMed. Years included in the search were 1980 (the year awareness of Alzheimer's disease began to become more prominent in the public domain due to the establishment of the Alzheimer's Association) to the present. Keywords used in this search included medical student, attitude, dementia, education, personhood, language, geriatrics, aging, older adult, patient-centered care.

#### **Attitudes Toward Aging**

Attitudes are known to exert a powerful influence on a range of behaviors. Since the 1940s, social psychologists have defined an attitude as: a response to a person, object, or event that combines three components – emotional, cognitive and behavioral. Each of these are on a positive to negative continuum, such as pleasurable to unpleasurable affect, favorable to unfavorable cognition, and supportive to hostile behavior (Breckler, 1984).

Over the past 50 years, a wide body of literature has examined attitudes toward older adults. A review by Hess (2006) found attitudes toward older adults are generally negative. The results of individual studies have been mixed, but a meta-analysis of 232 effect sizes found that individuals of all ages and backgrounds viewed older people as significantly less attractive and competent than younger people (Kite, Stockdale, Whitely, & Johnson, 2005). Attitudes toward older people are influenced by many factors, including their health (Gekoski & Knox, 1990), individuals' exposure to older people (Curl, Simons & Larkin, 2005), and education about aging and older people (Cottle & Glover, 2007; Snyder, 2006). Older adults with disabilities may be seen in a particularly negative light (Kahana et al., 1996; Stone, 2003).

Stereotypes of aging and old age seem to form in childhood (DePallo et al. 1995; Isaacs & Bearison, 1986). For example, books and media often contain unfavorable images of older adults and, as a consequence of repeated exposure to these materials, many younger persons form negative stereotypes of older adults at a young age (Sorgman & Sorenson, 2001). Strong and negative stereotypes toward older persons are found in college-age students (Robinson & Umphrey, 2006). Likewise, many medical students enter their curriculum with negative attitudes about older persons and the concept that careers working with older persons are often not valued by professionals and laypeople alike (Institute of Medicine, 2008; Moody, 2006; Reuben et al., 1996). Fitzgerald et al. (2003) surveyed the incoming medical school class at the University of Michigan and found that they had minimal knowledge about aging, moderately positive attitudes toward older adults, and low interest in geriatric medicine; however, having more positive



attitudes toward older adults and having cared for older persons prior to medical school were associated with greater interest in geriatric medicine.

Bagri and Tiberius (2010) conducted an interpretative phenomenological analysis to ascertain 34 medical students' perspectives on geriatrics after engaging in geriatric educational activities, beginning with exposure to healthy, community-dwelling older adults in the preclinical years followed by four weeks in a Geriatric Evaluation and Management Unit and a community living center (nursing home) affiliated with the Veterans Affairs Medical Center. Using focus group methodology, 17 themes emerged that elaborated on the students' perspectives on geriatrics. Students articulated the lack of intellectual stimulation more often than any other concern. They also expressed despair at the futility of care, were depressed by the decline and death of their patients, were frustrated by low reimbursement rates and low prestige despite fellowship training, were concerned about patients' unrealistic expectations and opportunities for litigation, felt unsure how to handle ethical dilemmas, and found communicating with older adults to be enjoyable but time consuming and challenging. The students also felt that they had too much exposure to geriatrics in medical school, a result the authors found particularly troubling because the negative perceptions and attitudes likely limit the effectiveness of teaching efforts. Using the Theory of Reasoned Action (Ajzen & Fishbein, 1980) that proposes a relationship between attitudes and behavior, they recommend that the quality of geriatric educational experiences be modified. In the preclinical years, they suggested that a separate geriatrics track is not the best way to ensure that students acquire best

practices toward older adults and that an integrated curriculum may be more relevant to their future careers.

### **Attitudes About Dementia**

Since over half of people over age 85 are expected to develop cognitive impairment, comparatively few studies have examined attitudes toward individuals with dementia. On one hand, researchers have found that dementia carries a negative stigma (Jolley & Benbow, 2000; Werner & Heinik, 2008); however, to date the literature on stigma in dementia is very limited.

The origin of the word, stigma, comes from the Greek term *stigma*, meaning to literally “mark or brand.” Goffman (1963) wrote that in ancient times “signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor - a blemished person, ritually polluted, to be avoided, especially in public places” (p. 1). Goffman (1963) eventually defined stigma as an attribute, behavior, or reputation, which is socially discrediting in a particular way and the stigmatizing process as causing an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.

The diagnosis or label of dementia is often stigmatizing. For example, Askham (1995) found that caregivers in long-term care settings described residents with dementia more negatively than positively, and Kahana and colleagues (1996) found that nursing home workers evaluated healthy older people more positively than those with Alzheimer’s disease. In a study comparing perceived stigma in persons with Alzheimer’s

and persons with Parkinson's disease, Burgener and Berger (2008) observed that the former group experienced significantly more internalized shame.

People living with Alzheimer's are sensitive to others' reactions to their diagnosis (Langdon, Eagle & Warner, 2007) and engage in negative self-stereotyping (Scholl & Sabat, 2008). In a survey conducted by Alzheimer's Disease International (2012), 40% of persons with dementia reported being treated negatively, including loss of friends and isolation. One in four cited stigma as a reason to conceal their diagnosis from others. These studies fit with Goffman's (1963) conceptualization of stigma.

Link and Phelan (2001) suggest that people with Alzheimer's disease and progressive memory loss are often labeled as different from the norm, subjected to stereotyping from persons without memory loss, and experience loss of status. These misconceptions can prevent people from acknowledging their symptoms and obtaining the help they need; in addition to lowering their self-esteem and psychological well-being. They are often 'placed' in situations (e.g., long term care) where they have no power over the decision-making that affects their lives. And, it is these organizations that can behave in ways that are unhelpful, emphasizing the symptoms of dementia rather than supporting the abilities that people with dementia continue to have.

On the other hand, lay community members (Werner, 2005; Werner & Davidson, 2004) and health professionals (Norbergh, Helin, Dahl, Hellzen, & Asplund, 2006; Zimmerman et al., 2005) also report positive attitudes about individuals with dementia. Among college students (Lundquist & Ready, 2008) and caregivers (Chu, 2004; Zimmerman et al., 2005), contact with people with dementia is correlated with these

more positive responses, particularly when relationships are strengthened with the kind of communication that occurs in programs that encourage creative expression (Basting, 2003; Fritsch et al., 2009;). These findings suggest that attitudes toward dementia have positive elements and that programs that encourage meaningful contact with persons with dementia can foster attitude change.

### **Education and Training in Aging**

Data suggest that students of multiple health disciplines hold negative attitudes toward older persons until they spend time with the older population or experientially learn about the aging process (Paris et al., 1997; Schuldberg, 2005). Early exposure to healthy (versus very ill) older people contributes to positive attitudes toward older patients and geriatric practice (Alford, Miles, Palmer & Espino, 2001). Ferrario, Freeman, Nellett, and Scheel (2008) proposed the importance of key nursing curriculum enhancements using successful aging as an organizing framework, developing faculty as aging specialists, and requiring coursework and clinical experiences with older adults. Volunteer nursing students completed knowledge and attitude surveys before and after a health and aging course in addition to a clinical practicum in a long-term care setting. Results revealed that students articulated more positive views about aging after their experience.

Westmoreland et al. (2009) at Indiana University School of Medicine, designed a study aimed to improve attitudes toward older adults among first and second year medical students through the use of reflective writing exercises and dialogue with a 'Council of Elders,' a panel of active healthy older adults who presented themselves as

senior instructors to trainees. The concept of a 'Council of Elders' as 'Senior Faculty' was first used successfully for resident education at Harvard's Cambridge Primary Care Residency Training Program (Katz et al., 2000). The researchers found that a 90-minute older adult session helped change negative or reinforce positive attitudes toward older adults.

Paris et al. (1997) measured medical students' attitudes about aging and found that students who had taken courses in aging or had exposure to a nursing home setting had more positive attitudes than students who had limited experience with older adults. Schulberg (2005) had social work students experience the characteristics of aging through simulation tasks, such as wearing glasses to blur their vision and writing with gloves that simulated motor impairments common in older adults. After experiencing some of the changes in aging, the students expressed more compassionate attitudes toward the older adult population.

Service-learning is an experiential teaching component added to traditional course work to provide experience outside the classroom. Studies indicate that students who participate in such a program with older adults express more compassionate attitudes and a better understanding of aging after completing intergenerational service learning. Questionnaires administered pre-service and post-service learning revealed improvements in compassionate attitudes about aging and a better understating of aging (Blieszner & Artale, 2001; Hanks & Icenogle, 2001; Whitbourne, Collins, & Skultety, 2001). Furthermore, students reported that the service-learning experience was highly

educational and personally meaningful (Whitbourne et al., 2001). Until recently, however, there was little review of the experimental rigor of these studies.

Brown, Kother and Wielandt (2011) conducted a critical literature review to determine the strength of the evidence for interventions aimed at modifying negative and ageist values and beliefs held by health care providers and students. They found that the overall evidence was “weak to moderate” and called for more rigorous study design utilizing random sampling and control groups and outcome measures that have strong psychometric properties, in addition to better justification for sample sizes. The studies lacked homogeneity in that they studied a wide variety of health care students and used many different outcome measures and interventions. However, what was identified as a “positive trend” was the use of in-person exposure and interaction with older adults.

### **Expanding Geriatric Curricula**

In response to the demographic social reality of an expanding aging population, the availability of geriatric curricula has expanded in the last several years. The John A. Hartford Foundation has catalyzed this process and Hartford Foundation programs have helped many U.S. medical schools to expand their undergraduate geriatric content, (Anderson, 2004). The Donald W. Reynolds Foundation’s Aging and Quality of Life Program has also provided financial support to several schools with the general goal of strengthening physicians’ training in geriatrics (Donald W. Reynolds Foundation, 2008).

Some clinical teaching initiatives have been started in the freshman year of medical school (Adelman et al., 2007; Supiano et al., 2007). In 2000 and 2001, the Association of American Medical Colleges (AAMC) and the John A. Hartford

Foundation, in an effort to enhance geriatric and gerontology curricula in schools of medicine, nursing, and social work, awarded 40 United States medical schools nearly \$5 million to develop integrated geriatrics curricula spanning the four years of undergraduate medical education. Programs in nursing and social work were also funded by the Hartford Foundation. Twenty medical schools implemented senior mentoring programs (SMP) in conjunction with traditional medical education techniques (Eleazar, Stewart, Wieland, Anderson & Simpson, 2009). These programs provided students with direct personal experiences with older adults for the purpose of improving attitudes toward and reducing stereotypes about older people thereby leading to enhanced patient care.

These efforts have yielded some results; 64% of medical schools in a 2005 survey reported specific learning objectives relating to geriatrics (Eleazer et al., 2005). In 2007, the Association of American Medical Colleges adopted core competencies in geriatric medicine for graduating medical students to assure competent care for older patients by new interns.

Alford et al. (2001) described results of a geriatrics educational program for first year medical students with healthy older adults that revealed an increase in awareness of geriatrics and comfort with older people. In terms of providing a mentorship opportunity, one student commented on the shift in his perspective – thinking he was going to do someone a favor – ‘visiting a lonely old sick person’ (p. 785), but found the older person did him a favor, helping him become a better doctor. The authors concluded that the program may have had an impact on ageist impressions and stereotypes not only of older

people, but with people of all groups. However, there was little change in career aspirations.

Emory University's School of Medicine revised its curriculum in 2007, combining clinical medicine and basic sciences in the first 18 months and as part of its first section on 'The Healthy Human,' they included a weeklong module on aging for first year medical students (Eskildsen & Flacker, 2009). Researchers conducted a study to evaluate attitudes and knowledge about aging issues before and after the course. The course included five days of sessions on topics ranging from molecular biology to societal aspects of aging. Students completed a pre/post survey including the University of California at Los Angeles Geriatrics Attitudes Scale and the Facts on Aging Quiz-1. The researchers found that the weeklong course on aging significantly improved students' attitudes toward elderly people and their knowledge base on aging.

### **Senior Mentoring Programs**

Eleazar et al. (2009) conducted an evaluation of ten of the Senior Mentoring Programs and found that, in spite of years of research showing mostly negative student attitudes toward older adults, the universal goal of positively influencing student attitudes toward older adults through the senior mentoring programs was "resoundingly achieved." Data included: student attitude measures, student evaluations, student focus groups, student written narratives, and site visit interviews and focus groups independent of program duration or structure. The evaluation also found that the attitude formation observed in students went well beyond the much-researched matter of negative stereotypes toward older adults. Faculty and staff were satisfied that student attitudes



toward older adults were generally positive and realistic as a result of the senior mentoring program experience, but Eleazar et al. (2009) found that many thought the student-mentor experience might also be influencing the formation of something deeper; perhaps student empathy, patient-centeredness, or the ability to “individualize” people.

Similarly, the Medical College of Wisconsin offered a small group of first and second year students an older adult mentor as an alternative to a traditional physician mentor (Bates, Cohan, Bragg, & Bedinghaus, 2006). A qualitative analysis of student-written reports identified that students reported a positive attitude change and improved communication with older adults; the development of meaningful relationships with their mentors, the value of interdisciplinary care for older adults, and overall reported a positive experience in the program.

However, comparison groups were seldom used in the Senior Mentoring Programs. An exception was Bernard et al. (2003) who developed a Senior Mentoring Program at the University of Oklahoma College of Medicine pairing first year medical students from the class of 2002, with older volunteers. Students completed a series of four structured interviews with older adults where students elicited family and social history, functionality, medical history, review of systems and finally values, beliefs and wishes as they relate to the older adults’ health and health care. This intervention was measured by the Aging Semantic Differential (ASD), (Rosencranz & McNevin, 1969), an used instrument in gerontological and geriatric education to assess the stereotypic attitudes young people have toward older adults. Scores were compared to the previous year’s first year medical school class (2001). The ASD scores were significantly greater

for the intervention group ( $p=.002$ ) appearing to support the conclusion that those involved in the Senior Mentors program had a more positive attitude toward older adults. Again, this is in keeping with studies that have demonstrated a beneficial effect of the exposure of medical students to the geriatric population, particularly early in their training. However, the authors' (Bernard et al., 2003) concern was whether or not this positive effect persisted through the clinical training years and whether or not it influences ultimate career choices or, in other words, "does it stick?" Diachun, Dumbrell, Byrne, and Esbaugh (2006) attempted to answer this question by comparing a three-hour didactic lecture to a three-hour experiential learning session. Although initially, the experiential group demonstrated a better knowledge score, at one-year follow-up there was no significant difference in knowledge, attitudes toward older people, or interest in geriatric medicine between the didactic and experiential groups. However, the students who participated in the experiential or didactic sessions demonstrated better attitude scores than those who had not attended either educational intervention. The study by Diachun et al. (2006) challenges the belief that an experiential approach is a superior training method to a didactic approach.

Lastly, Duke, Cohen and Novak (2009) developed a framework for a geriatric mentoring program to examine first year medical student attitudes toward older adults after participation. The students volunteered ( $n=55$ ) to participate in a series of classes including a lecture on ageism and an orientation followed by interactions with "non-acute" older adults in an assisted living facility. The goal was not to impart medical knowledge as much as to develop a framework for appreciation of older adults and to

submit narrative expressions of their experience following their interaction. A survey of attitudes following the experience showed a trend towards improvement of student attitudes towards older adults.

### **Education and Training in Dementia**

As described, although weak methodologically, there is some evidence that undergraduate teaching interventions in geriatrics may improve the knowledge, skills and attitudes of medical students. However, little has been written specific to medical students and persons with dementia. A study by Goldstein, MaLossi, Kye and Young (1999) evaluating the effect of a one-week course on dementia for medical students did report greater self-confidence in some aspects of dementia care among intervention participants as compared with control subjects; however, intervention participants were self-selected and practice outcomes were self-reported, limiting the significance of the findings. Hsieh, Arenson, Eanes and Sifri (2010) qualitatively analyzed reflection papers of 48 third-year medical students following a one-day experience working in a continuing care retirement community. The narrative analysis revealed six themes: (1) The initial exposure to dementia; (2) confronting death and dying; (3) the diversity of care and services for the elderly; (4) the cost of care for the elderly; (5) the possibility that seniors can lead active lives if given the opportunity; and (6) the rewards of the health care team-patient relationship. While students reported increased positive responses toward healthier more active older adults with whom they came in contact, there were mixed responses toward persons with dementia. Many students found it difficult to interact with persons with dementia and found it depressing, but were struck by how medical

professionals met the challenges of caring for persons with dementia. Hsieh et al. (2010) reflected that the experience seemed to increase students' sensitivity to the needs of these individuals and the development of empathy with their condition.

Fruhauf, Jarrott, and Lambert-Shute (2004) developed a training program designed to facilitate comfort with older adults with dementia in an adult day service setting. This intervention targeted undergraduate sociology students who participated in a service-learning program as part of a gerontology course. Half the students received the training program (dementia education and communication skills instruction and a structured activity they could complete with the adult day services client) and were compared to service-learners at dementia care programs who did not receive specialized training. Fruhauf et al. found that the trained group had higher ratings on attitudes toward not only the site clients, but to older adults in general and had more hours of contact with persons with dementia at their site than the comparison group.

Siegler, Cotter, Goldberg-Glen, Brice, and Ellis (1996) designed an interdisciplinary, experiential course, "Living with Dementia" to include an opportunity to spend time with dementia patients and their caregivers in non-medical settings. One goal of the course was to allow medical, nursing and social work students to witness first hand what it is like to live with dementia. The course consisted of two components, a seminar series supplemented by reading assignments and an experiential opportunity, consisting of visits with persons with dementia and their families. Results indicated that the course was successful. Course evaluations and content analysis of diaries kept by students demonstrated that they were receptive to the materials and incorporated the most

important concepts into their observations and understanding of dementia. They felt the experiential opportunity was the most valuable part of the course. Results were not provided per discipline. A second goal of the course, to promote understanding of other disciplines, was less successful. Although similar in age, students were at different levels of role development (1<sup>st</sup> year medical students, 4<sup>th</sup> year nursing students and 2<sup>nd</sup> year social work students), which was thought to contribute to this finding.

Beck (1996) explored the meaning of nursing students' experiences caring for cognitively impaired elders. Five major themes emerged in this phenomenological study: (1) nursing students experienced a myriad of emotions such as frustration, sadness, fear and empathy; (2) caring for cognitively impaired people presented difficult challenges such as combative and verbally abusive behavior; (3) nursing students utilized multiple care approaches such as non-verbal techniques, short, simple communication strategies, flexibility and a calm quiet manner; (4) negative consequences ensued for some nursing students who experienced hardening to the patient's behavior and a decrease in their sense of compassion; and (5) the positive consequences far outweighed the negative in that some students learned not to be so afraid and recognized that each patient deserves to be treated with respect and dignity.

A recent study by George, Stuckey and Whitehead (2013) examined fourth year medical students' self-reported attitudes toward persons with advanced Alzheimer's disease and related disorders before and after engaging in an arts-based creative storytelling intervention at a nursing home called TimeSlips (Fritsch et al., 2009). The TimeSlips program encourages participants to use their imagination to create poems that

tell stories. Using the Dementia Attitudes Scale (O'Connor & McFadden, 2010), the results of the study confirmed that this intervention can significantly improve medical students' attitudes toward persons with dementia.

Tullo and Allan (2011) conducted an international review of recommendations for medical education on dementia and empirical research on teaching interventions concerning dementia. They found that undergraduate curricula show considerable variation in the delivery of teaching about dementia. Qualitative feedback has shown evidence that the education has been positively received; however, it has not translated into consistent demonstrable improvement in knowledge, skills or attitudes.

### **The Healthcare Experience**

We live in a society that highly values independence, autonomy, and intact cognitive capacity. Persons with Alzheimer's disease are concerned with preserving as many of these attributes as possible. In a qualitative analysis of an early stage support group, members' reflections indicate that they want opportunities where they are not marginalized – via societal perceptions (the media), by family and friends, and in the doctors' office (Morhardt, Sherrell, & Gross, 2003). A common complaint from those with dementia is the lack of communication with the affected person; rather, the communication is directed toward spouses or other family caregivers (Morhardt et al., 2003; Young, 2002).

Patients with dementia and their families are often frustrated by the dehumanizing experience they feel in the healthcare experience and the lack of a 'holistic' approach (Keady & Gilliard, 2002; Young, 2002). For example, Keady and Gilliard (2002)

describe the experience of persons with memory loss undergoing neuropsychological assessment. Patients described their experience as inducing feelings of distress and anxiety over their performance. The experience, a focus on losses, was seen as threatening to one's sense of self. Young (2002) reported results from a series of focus groups with persons with dementia and their caregivers regarding their medical encounters. They overwhelmingly found them to be very unsatisfactory and frustrating. Many remarked that the medical professionals 'disappointed them' (p. 38). Two types of unsatisfactory encounters were documented. First, both the person with dementia and their families were disappointed by the medical care received and second, they were very dissatisfied with communication and interaction patterns. They described a strictly "medical nature to the visit" with no regard to providing treatment and management options. "The interaction patterns were strictly disease-oriented, not person-oriented" (p. 39).

### **Summary**

Researchers who have designed interventions to increase knowledge, foster positive attitudes and modify behavioral beliefs regarding older adults in general demonstrate an overall positive effect; however, a recent critical review of the literature to evaluate methodological quality of these relevant outcome studies found that only one of fifteen studies that met the inclusion criteria was rated as "strong" evidence and the remainder lacked methodological rigor. Such findings make it difficult to evaluate the usefulness of these educational interventions (Brown et al., 2011). Additionally, very

few studies have focused on educating students regarding the specific needs of older adults with cognitive impairment.

Overall, there is a need for early intervention in medical education to work with our growing older adult population and persons with dementia. It is expected that improving medical education on dementia will ultimately result in benefit to patients; however, based on this literature review, dementia education for medical and non-medical students is much less prevalent than education on aging in general. The results of this study have the potential to help fill this gap.

### **Theoretical Framework**

The literature review of studies on attitudes toward aging and dementia and the results of educational interventions on students of medicine and other disciplines revealed that increased and meaningful contact contributes to change in negative attitudes toward older adults and those with dementia. Additionally, a ‘new culture’ of dementia care (Kitwood, 1997, p. 136) has been embraced by programs and services devoted to promoting and sustaining life quality for persons with dementia, recognizing the importance of the attitudes of the people surrounding the person with dementia toward the individual’s sense of self. This new culture construes personhood as ‘a standing or status bestowed upon one human being by others, in the context of relationship and social being’ (p. 8). In addition to the view of dementia as a collection of neuropsychological symptoms reflecting brain pathology, this perspective affirms the unique personal histories of individuals living with dementia in particular social environments. As a result, the present study was grounded this study in contact theory (Allport, 1954), theory



of personhood (Kitwood, 1997; Rogers, 1961) and social constructionism (Berger & Luckman, 1967; Sabat, 1992, 2001).

### **The Contact Hypothesis/Intergroup Contact Theory**

Credited to Gordon W. Allport (1954) the Contact Hypothesis, or Intergroup Contact Theory, states that under appropriate conditions interpersonal contact is one of the most effective ways to reduce prejudice between majority and minority group members. Allport referred to the terms in-group as “a group to which someone belongs” and the term out-group as “a group to which someone does not belong” (p. 248).

Understanding the formation of human perception was pivotal to Allport’s theory of intergroup contact. As Allport explained:

Group differences are one thing; how we perceive them and think about them is quite another. Nothing that strikes our eyes or ears conveys its message directly to us. We always select and interpret our impressions of the surrounding world... What I sense, what I perceive, and what I think become blended into one single act of cognition. It is important that we never fall into the error of supposing that we perceive group characteristics directly. Perception is more than a simple physical phenomenon; it is a psychic function from which we may draw the most far-going conclusions regarding the inner life. (p.165)

Allport (1954) understood prejudices as a result of a hasty generalization made about a group based on incomplete or mistaken information. The basic rationale for the Contact Hypothesis is that prejudice can be reduced as one learns more about a category of people. A person’s beliefs can be modified by that person coming into contact with a member of a category or group and subsequently modifying or elaborating the beliefs about the group as a whole. Allport argued that, “Casual contact does not dispel

prejudice; it seems more likely to increase it” (p. 263). The reason, he explained, required an examination of the “perceptual situation in a casual contact” (p. 264).

Suppose that on the street or in a store one sees a visible out-group member. By the association of ideas there is likely to come to mind a recollection of rumor, hearsay, tradition, or stereotypes by which this out-group is known. Theoretically, every superficial contact we make with an out-group member could by the ‘law of frequency’ strengthen the adverse mental associations that we have. What is more, we are sensitized to perceive signs that will confirm our stereotypes. Casual contact, therefore, permits our thinking about out-groups to remain on an autistic level. We do not effectively communicate with the outsider, nor he with us. (p. 264)

Originally developed to foster optimal interracial contact, Allport’s theory has been utilized in linking a variety of different groups broadening its applicability by examining a variety of prejudice, attitude and contact effects toward a wide range of target groups, such as the elderly homosexuals, the mentally ill, disabled persons, and victims of AIDS (Pettigrew, 1998).

Intergenerational programs, designed to link members of younger and older generations for mutual benefit embody one way to foster positive contact and decrease social distance between generations (Caspi, 1984; Gladwell, 2003; Jarrott & Smith, 2010). Caspi (1984) first used contact theory to inform intergenerational research when he assessed the attitudes of children in an intergenerational program involving older adults as care workers. The children who had frequent and regular contact with the older adult aides had more positive attitudes towards older adults compared to a similar group of children without such contact. Caspi concluded that the frequent and regular opportunities for interaction were central to the children’s positive experiences.

Fruhauf et al. (2004) cites research by Gladwell (2003) that employed theory of contact to foster positive intergenerational contact for pre-school aged children and older adults finding that “levels of group social behavior and positive affect were higher among adult participants during the intergenerational activities compared to the adults’ unigenerational programming” (p. 39). Jarrott and Smith (2010) found that use of contact theory to inform intergenerational programming supported the goals of intergenerational contact; that is, higher levels of active engagement were observed in a contact theory based intergenerational program versus a traditional program where the tenets of contact theory were not employed.

The inter-group contact hypothesis proposes that under certain conditions intergroup contact will reduce prejudice and increase positive attitudes between the two groups (Pettigrew & Tropp, 2005); however, contact between social groups alone is not sufficient to produce respect, lessen prejudice, or promote an appreciation for individual or group differences (Berryman-Fink, 2006; Valentine & MacDonald, 2004). According to Valentine (2008), “The basis of Allport’s argument was that people are uncomfortable with the unknown and so feel anxious about encounters with difference” (p. 324).

Therefore, to effectively lessen feelings of anxiety and uncertainty between groups planned contact is required. “It is not the mere fact of contact that is decisive,” Allport (1954) argued, “it is the forms of resulting communication that matter... We must not assume that contact automatically solves the problem of prejudice. At most we can say that it creates a condition where friendly contacts and accurate social perceptions can occur” (p. 272). Tenets of contact theory include four named by Allport and when

achieved, promote positive contact between members of disparate groups. These tenets are (1) cooperation and (2) a shared goal; (3) the interactions must receive support from a key authority figures, stakeholders and tradition; and (4) participants must perceive themselves as possessing equal status within the contact situation.

The current study is the first to expand Allport's (1954) theory of intergroup contact to persons with dementia (mostly older adults) paired with young medical students. The following describes how the contact conditions were met in this study.

**Institutional support.** Allport's condition of authority, or institutional support, for intergroup contact has been widely supported and shown to be an important variable influencing positive affect among groups (Dovidio, Gaertner & Kawakami, 2003). Authorities not only provide structure, but can also promote greater contact. Additionally authority figures help to create a social climate which allows different attitudes to emerge (Gilbert, Fiske, & Lindzey, 1998).

The Buddy Program has been approved and supported by the researcher's center director since the program's inception (1997) as well as the medical school's dean of education. It has been the subject of university and medical school publications (Danzig, 2010; Weber, 2010) and is widely known throughout the medical school as a well-respected experiential opportunity.

**Common goals.** According to Allport (1954), "Goodwill contact without concrete goals accomplishes nothing. Groups gain nothing from artificially induced mutual admiration" (p. 279). In this study, students and their mentors (persons with

dementia) have mutual goals of building a relationship, sharing social histories and experiences.

**Intergroup cooperation.** One of the keys to successful contact is for both sides to participate jointly in a task, the completion of which is important to both groups (Allport, 1954). “Only the type of contact that leads people to do things together is likely to result in changed attitudes. It is the cooperative striving for the goal that engenders solidarity” (pp. 276-277). In this study, mentors and students mutually decide on shared activities throughout the course of the academic year. The activities are not assigned; they can meet with their ‘buddy’ at a time that is mutually convenient and the choice of activity is not controlled or specified by the research program.

**Equal status.** Allport argued that both groups should expect and perceive equal status in a contact situation (Pettigrew, 1998). Contact interactions would encourage each group to respect the other’s contributions by identifying their ability to benefit from the other group’s expertise (Dovidio et al., 1998). According to McClendon (1974), equal status increases the likelihood for perceived similarities between groups and enhances the likelihood for improvement in their relationship.

Typically the relationship between physicians and persons with dementia is unequal, with the physician in a position of power. In this study, first year medical students and persons with dementia (mentors) have equal status. The experience and relationship is developed outside of a clinical setting. Each individual has something to share with the other. There is equal respect for autonomy and the ability to contribute.

In summary, Allport's (1954) theory posits that when all four contact conditions—institutional support, equal status, common goals, and intergroup cooperation are present in an intergroup situation, a reduction in anxiety between groups is likely to occur as they interact with each other. While Allport's four conditions of contact have been empirically demonstrated in a variety of intergroup contact situations, no known study has applied this framework to the relationship between persons with dementia and first year medical students.

### **Theory of Personhood**

The term personhood is generally used to describe the fundamental attributes of a person and the uniqueness of each human being (Dewing, 2008). Because dementia is associated with a progressive decline in cognitive functions, the disease has historically been assumed to strip the individual of their personhood status, leading for example to a 'loss of self' (Cohen & Eisdorfer, 1986; Herskovits, 1995). People living with dementia are described as 'the living dead' or 'an empty shell' (Gubrium, 1986) and the experience of the person living with a person with dementia as the "ongoing funeral" (Kapust, 1982). The loss of cognitive functioning in people with the disease is linked in these images to the notion that, with the progression of the disease, personhood or the 'inner person,' vanishes.

Bartlett and O'Connor (2007) posit that "personhood is a contested concept" (p. 109) with historical roots in the Enlightenment and the philosophies of Rene Descartes (1596-1650) and John Locke (1632-1704) on what it means to be a person. These

“logical empiricist, traditional views of personhood focus largely on cognitive abilities, such as consciousness, rationality, intentionality, memory, reciprocity and the capacity to communicate” (p. 109).

In the late 1980's, the notion of 'personhood' was introduced into the dementia literature as a critical component of the dementia experience and reconceptualized as socially constructed by and within one's interactional environment. Kitwood (1997), most recognized for pioneering this approach, provided a model of dementia which highlights the interaction between neurological impairment, the psychology of the person with dementia and the social environment, and strongly advocated for the respect of personhood.

Kitwood (1997) defined personhood as “a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements” (p. 7). The theory of personhood (Kitwood, 1997) addresses the rights and respects due to all individuals, with a focus on persons with dementia. His work derives from an assertion about the nature of being, with the premise that a person with dementia remains a person throughout their disabling experiences. Thus, every person has an absolute value and so there is an obligation “to treat each other with deep respect” (p. 8). He coined the term “malignant social psychology” and developed a clinical model describing how social actors, including doctors and nurses, contribute to the “social death” (Sweeting & Gilhooly, 1997) of the person with dementia.

In other words, Kitwood and those who have worked with his theoretical model, argue that the loss of self in dementia arises not solely from the disease but rather from

the way other people treat the person with dementia (Sabat, 1994; Reifler & Larson, 1990). Kitwood (1990) called this a “dialectical process explanatory model”; that is, the experience of living with dementia is the result of a dialectical interplay between neurological impairment and psychosocial factors – health, individual psychology and the environment with particular emphasis on the social context. Kitwood’s dialectical process model of dementia allows for the environment to have as much effect on the brain as the brain has on the person’s abilities. For Kitwood and Bredin (1992) the most disabling effects of brain disease are to be found not in functional impairment, but in threats to one’s sense of self and one’s personhood.

MacRae (2010) in her qualitative analysis of interviews with nine persons with early stage Alzheimer’s disease, confirmed that persons with early stage dementia can, “with resilience and resourcefulness, respond to the threat to self the disease presents, finding ways to manage and preserve identity” (p. 302). She found that “most participants did not believe they had changed very much, nor did they express a great deal of concern about potential changes in self” (p. 302). “A positive sense of self was sustained, in large part, because their social experience was positive” (p. 302). She concluded that, although self-construction is accomplished by interaction with others, “individuals actively participate in the construction of their own identities” (p. 302).

Harrison (1993) also offered the view that personhood is defined by feelings, sensations, emotive responses, and the ability to live in relationships; that is, experience interdependence and interconnectedness. She held that attention should be paid to individuals’ remaining strengths, the positive functions and characteristics. Although the



disease can threaten personhood, appreciating the integrity and fullness of the social life of the person with dementia may help to preserve it. It has been found that selfhood remains in people with dementia if they are nurtured by personally and socially supportive relationships (Clare, 2003).

Theories of personhood can be credited to a shift in research that captures the perspectives of persons with dementia (Harris, 2002; Wilkinson, 2002), documenting that persons are aware of their situation (Clare, 2003), and can contribute important and unique insights about their experiences and needs. Bartlett and O'Connor (2006) reflect that "since the introduction of personhood in the dementia literature, research and practice has shifted from failing to even consider whether persons with dementia have anything to say, to acknowledging that indeed they do and recognizing the importance of hearing their perspectives" (p. 109). However, while recognizing the value and achievement of the attention to personhood in dementia care literature, they go on to challenge its boundaries; namely, (1) promoting an individualized lens for understanding the dementia experience versus macro level issues such as the impact of social structures related to disability, age, gender, ethnicity and social class that influence the lived experience; (2) that while personhood is grounded in the idea that a person with dementia 'counts', it does not necessarily promote the vision of someone with agency; that is, personhood is conferred on a person rather than seeing that person as capable of exerting power and influence; and (3) because personhood is essentially 'apolitical' and primarily concerned with 'psychological and health matters such as love, morality, spirituality and well being' (p. 110), it does not promote a discussion on how people's situations are

influenced in terms of power relations; e.g., ‘caring’ might sometimes have more to do with power and control than with values of trust and giving, in addition to overlooking experiences of discrimination.

Bartlett and O’Connor (2006) propose a “citizenship” lens in contrast to the personhood perspective. They cite citizenship as a “status bestowed on those who are full members of a community” (p. 111). From a Foucauldian perspective the situation of persons with dementia has become medicalized and, in turn, disempowering to people with dementia and their families. A conceptual shift to the citizenship lens means that people with dementia are clearly seen and treated as important players with the power to shape and instigate the research agenda.

**The emergence of person-centered care.** Carl Rogers (1961), a humanistic psychologist, founded the “person-centered” approach to care. Rogers maintained that in relationship, one must have unconditional positive regard, genuineness and empathic understanding. This required an open caring of the person without judgment and acceptance of the person as they are. Central to person-centered care is the idea that every person has an innate need for emotional or physical pleasure such as love, affection, attention and nurturance (Holosko, Skinner, & Patterson, 2012).

Rogers (1980) proposed that a person-centered approach, based on acceptance, caring, empathy, sensitivity, and active listening, promotes optimal human growth. He believed that in order to actualize human growth in late life, individuals should have access to, and opportunities for ongoing learning, personal challenges, and close and intimate relationships. He argued that human capacity for growth does not diminish with

age, nor does the need for growth become less relevant as we age. The emphasis of person-centered care is on well-being and quality of life as defined by the individual (Crandell, White, Schuldheis & Talerico, 2007).

Kitwood (1997) proposed that family members and professional caregivers are responsible for providing care that supports the individual's *personhood*, the respect and trust given to a human within the context of relationship and social being. Personhood of any individual, regardless of age or ability, is supported by meeting basic human needs, including (a) attachment, (b) comfort, (c) identity, (d) occupation, and (e) inclusion.

Castillo (2011), a physician and medical anthropologist, describes the first step to treating patients with dementia differently is to begin to recognize cultural notions of personhood, of what makes a person a person, that shape the meaning and experience of dementia. Clinicians guided by the theory of personhood, strive to support the history and individuality of each client with dementia. Clients receiving person-centered care are treated with respect. Research has linked person-centered care with greater well-being and fewer problematic behaviors among adults with dementia (Kitwood, 1995). Dewing (2008) cites McCormack and Reeds' (2006) editorial "Person-centered practice requires healthcare professionals to put the person first and the evidence base for technical or clinical interventions second" (p. 7).

Fritsch et al. (2009) showed that staff working with residents using TimeSlips, an improvisational storytelling method, in five nursing home facilities, had more positive views of persons with dementia at the end of a 10-week period than staff who had engaged in their usual activities at five control facilities. Because participation in

creative engagement programs enables persons with dementia to reveal preserved abilities and insights about the world, these programs may also help families and friends to view residents in a different light. Another study evaluated another creative engagement program, Memories in the Making (Kinney & Rentz, 2005), discovering that engagement in self-expression through the visual arts resulted in significantly more interest, sustained attention, pleasure, self-esteem and normalcy during participation compared to participation in more traditional adult day center activities, such as current events and crafts.

These types of creative activities promote relationality and affirm personhood. These and other ‘new culture’ developments in adult day centers, long term care residences and community-based programs may also encourage positive attitude changes toward people with dementia among students, direct care workers, family members, and community volunteers.

**Social constructionism.** Consistent with the theory of personhood is the social constructionist view of the self. The social constructionist position proposes that reality is socially constructed through human action and that knowledge is socially produced and reproduced, emerging from the ordering and interpretation of ‘facts’ (Berger & Luckmann, 1967). Social constructionists argue that all reality has both subjective and relative aspects and that knowledge is formed from the views and meanings that people, situated in their own history and context, ascribe to a particular experience (Shotter & Gergen, 1989). Besthorn (2007) describes social constructionism as the place when “humans are active participants and co-constructors with each other in creating and

comprehending experience....We construct our worlds through a complex mix of conceptualizations, perceptions, values, explanations, language experiences, narratives, dialogues, and conversations – all of which occur in relationship to others” (pp.173-174). Rather than a true reality, there are multiple, constructed realities, that are subjective and influenced by the situational context.

### **Social Constructionism and Dementia**

The role of others’ perceptions is critical in the construction of a person's social self. In other words, personhood arises out of social interaction. The social constructionist theory can serve as a framework for understanding the expression of self in people with dementia and the impact of communication and social constructs on the maintenance of or threat to selfhood (Clare, 2003; Sabat, 2001). Personhood is the result of social interactions rather than emanating from the individual alone. We “make and unmake” each other through social interactions (Castillo, 2011). Having a diagnosis of Alzheimer's disease affects how a person's actions are interpreted and contributes to the construction of a social identity as a dysfunctional patient.

Therefore, maintaining a sense of personhood requires the cooperation of others (Sabat, 2002) and interactions with others can positively or negatively affect the ability of the person with dementia to maintain and communicate their sense of self. Stereotyping and pathologizing the person with dementia diminishes and marginalizes them. People diagnosed with Alzheimer's disease struggle to maintain their social selves when others do not cooperate with their attempted constructions of these selves. Persons with dementia react to how they are treated (Sabat, 2001) and this treatment by others can

have a profound effect on the persons' subjective experience, their quality of life and their ability to live meaningfully.

Sabat and Collins (1999) identified the importance of support in maintaining a sense of self to the self-esteem of persons with dementia. Loss of self-esteem can be perpetuated by the failure to recognize the social self of persons with dementia and result in a focus on lost abilities and defects. The authors concluded that the maintenance of self-esteem, decreasing perceptions of being a burden on others, and a decreasing anxiety can be facilitated by others in allowing persons with dementia to express and maintain their sense of self and personhood.

When others position the person with dementia as "demented," they might misinterpret their efforts to maintain their own identity (McLean, 2007). Individuals still possess an intact sense of personal identity and have the ability to construct social identities when they obtain the necessary cooperation of others (Sabat & Collins, 1999).

Kitwood (1997) suggested that the way in which people with dementia are treated has a significant impact on their experience of the disease and its progression. Kitwood wrote, "If we follow the development of any person's dementing condition closely, again and again we will come to see how the social and interpersonal factors come into play, either adding to the difficulties arising from neurological impairment, or helping to lessen their effects" (p. 40).

This research focuses on the impact of social context on the experience of individuals suffering from dementia, with particular emphasis on the interaction of social, psychological and neurological factors in shaping this experience. This theoretical

position requires clinicians to have what Hughes, Louw, and Sabat (2006) call “whole sight” – that people should be treated as “wholes” with attention not only to their biology, but also to their psychology, their social and ethical concerns, and the cultural and spiritual aspects of their lives and their relationships, which is quite consistent with a social work perspective. This depersonalization of persons with Alzheimer’s disease illustrates Kitwood’s (1997) concept of ‘malignant social psychology’ or ‘malignant positioning’.

Sabat and Harré (1992) argue that even in the more advanced stages of Alzheimer’s disease, there is a self “that remains intact despite the debilitating effects of the disorder” (p. 444). As described by Coulter (1981) and Harré (1983) selfhood is publicly manifested in discourse such as telling stories about oneself, taking the responsibility for one’s actions, expressing doubt, taking an interest in self care, and stating the unfairness of something. Cassel (1982) describes the different facets of a person as having a past, having cultural background, roles, relationships with ‘others’, being political, engaging in action and creation, performing regular behaviors, having a body, a secret life, a perceived future and a transcendent or spiritual dimension. Cassel stresses that no person exists without ‘others’ and it is through relationship with ‘others’ experience of a full sense of being a person evolves. Hughes et al. (2006) describes the theology based on the African notion of *ubuntu* which Nobel Peace Prize winner and Archbishop Emeritus of Cape Town, Desmond Tutu characterized as: ‘...each individual’s humanity is ideally expressed in relationship with others’; or more straightforwardly, ‘a person depends on other people to be a person’ (Battle, 1997 as

cited by Hughes et al., 2006, p. 26).

Harris and Sterin (1999) analyzed data from in-depth interviews with 17 individuals diagnosed with early stage Alzheimer's disease. Their aim was to better understand the diagnosed person's sense of self and identity and the social milieus that might affirm rather than undermine this sense of self. They found that the social interactions of the people they interviewed had a significant impact on their self-esteem and their capacity to preserve "their held self definition" (p. 255).

More recently Clare (2003) carried out a qualitative study using interpretative phenomenological analysis to investigate awareness in people with early stage Alzheimer's disease. She interviewed 12 individuals with this diagnosis to explore the influence of psychosocial factors on their awareness of their illness. From these data, she developed a model of construction of awareness in early stage Alzheimer's disease that acknowledges the role of biological factors and mechanisms but gives primacy to psychosocial factors and self-concept in understanding whether a sufferer demonstrates awareness of having the disease.

### **Summary**

The theories of interpersonal contact, personhood/person centered-care and social constructionism provide the foundation for the creation and development of the program that is the focus of this dissertation, bringing together medical students and persons with dementia as their mentors in a non-clinical relationship. The tenets for all of these theoretical foundations have been met in the program design and in the methodological inquiry regarding the impact of this experience on participating medical students.



## CHAPTER FOUR

### METHODOLOGY

#### **Research Question**

The purpose of this study was to examine the experience of first year medical students and persons with dementia who take part in an experiential learning program called ‘The Buddy Program’. The overarching research question for this study was: What is the impact of an experiential learning and mentorship program with persons diagnosed with early stage dementia on first year medical students?

The specific aims of the Buddy Program were 1) to improve medical students’ knowledge and attitudes toward aging and dementia, and 2) to enhance the quality of life for persons with dementia and their families.

#### **Research Approach Description and Procedures**

##### **Interpretivist/Constructivist Paradigm**

The chosen research design encompasses qualitative methodology within an interpretivist/constructivist paradigm. The interpretivist/constructivist paradigm holds assumptions about the social world and subjectivist assumptions about epistemology and tries to understand the social world from the perspective of individual experience (Rossman & Rallis, 2001). It assumes reality as we know it is socially constructed (Mertens, 2005) through the meanings and understandings developed socially and experientially.

The interpretivist/constructivist paradigm grew out of the philosophy of Edmund Husserl's phenomenology and Wilhem Kiltney's and other German philosophers' study of interpretive understanding called hermeneutics (Mertens, 2005, p. 12 citing Eichelberger, 1989). The interpretivist/constructivist researcher tends to rely upon the participants' views of the situation being studied (Creswell, 2003, p. 8) and recognizes the impact of their own background and experiences on the research.

Constructivists do not generally begin with a theory, rather they 'generate or inductively develop a theory or pattern of meanings' (Creswell, 2003, p. 9) throughout the research process. The constructivist researcher tends to rely on qualitative data collection methods and analysis or a combination of both qualitative and quantitative methods. Quantitative data may be utilized in a way that supports or expands upon qualitative data and effectively deepens the description (MacKenzie & Knipe, 2006).

### **Qualitative Methodology**

The benefit of using qualitative data is that it focuses on "naturally occurring, ordinary events in natural settings" (Miles & Huberman, 1994, p.10). At the core, qualitative research focuses on the meanings, traits and defining characteristics of events, people, interactions, settings/cultures and experience. Berg (2007), a leading proponent of qualitative methods explained, "Quality refers to the what, how, when, and where of a thing – its essence and ambience. Qualitative research thus refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things" (p. 3).

Qualitative research methods emphasize interpretation and provide readers with

complete views; that is, an immersion in the environmental context and a deep conceptual understanding. Similar to Weber's concept of *Verstehen* (Tucker, 1965), qualitative researchers seek to provide a fully rounded empathic understanding of issues, concepts, processes and experiences.

Qualitative research relies on the process of analytic descriptions for “identification of recurrent patterns or themes to construct a cohesive representation of the data. These recurrent themes are then linked to concerns or issues in the ... literature – theoretical, conceptual, or applied – as you develop interpretations of what is happening in your setting (or interviews or documents or images) and what their words or images mean to the participants” (Warren & Karner, 2005, p. 190). As such, the analytic process in qualitative research is centered on researchers looking at their data, finding patterns and similarities across cases, times and instances and interpreting what these issues mean. The qualitative method in this study placed primary value on an understanding of the students' experience with the person with dementia through documentation of their dynamic social interaction.

### **Qualitative Content Analysis/Thematic Analysis**

Data analysis is a systematic search for meaning. It is a way to process qualitative data so that what has been learned can be communicated to others. Analysis means organizing and interrogating data in ways that allow researchers to see patterns, identify themes, discover relationships, develop explanations, make interpretations, mount critiques, or generate theories. It often involves synthesis, evaluation, interpretation, categorization, hypothesizing, comparison, and pattern finding. It always involves what H. F. Wolcott calls “mindwork”. . . Researchers always engage their own intellectual capacities to make sense of qualitative data. (Hatch, 2002, p. 148)

In this study, qualitative content/thematic analysis is the methodology used to analyze written text from first year medical students who were paired with persons with dementia over one academic year. Texts are viewed as reflective of the student's human experiences. Naturally occurring information offers rich descriptions of phenomena in a social context and reveals complex descriptions of people's "lived experience" (Miles & Huberman, 1994, p. 10). Content analysis is fairly unique among the qualitative methods in that it often utilizes quantitative analysis. However, qualitative content analysis goes beyond traditional quantitative content analysis, which focuses on the frequency of particular words or categories and is often criticized for missing the importance of the context in which those words or categories appear (Joffe & Yardley, 2004). In most instances, and especially when the product of such analysis is qualitative in focus, the emphasis remains on the text's meaning. The goal of content analysis is "to provide knowledge and understanding of the phenomenon under study" (Downe-Wamboldt, 1992, p. 314).

Qualitative content analysis allows researchers to systematically make inferences about social reality by recognizing patterns or themes (Hsieh & Shannon, 2005; Schreier, 2012) and is one of numerous research methods used to analyze text data. Other methods are ethnography, grounded theory, phenomenology and historical research (Hsieh & Shannon, 2005). Text data may be in oral, print, or electronic format and may be obtained from narrative responses, survey questions, interviews, focus groups, observations, or print media such as articles, books, or manuals (Kondracki, Wellman, & Amundson, 2002).

Hsieh and Shannon (2005) defined qualitative content analysis as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p. 1278). The process involves the identification of themes through “careful reading and re-reading of the data” (Rice & Ezzy, 1999, p. 258). In qualitative content analysis, the process of thematic analysis is used to organize qualitative information based on emerging patterns or themes. Boyatzis (1998) explained that thematic analysis is a “way of seeing” (p.1), and it allows a researcher to recognize patterns in data that on the surface appear random. Depending on the research question, the researcher can use themes to simply describe and organize the data or he or she can take a step further to interpret and make inferences about the observations.

Content thematic analysis requires the researcher to classify and organize the data for the development of themes and later analysis. Coding is “the widely accepted term for categorizing data: taking chunks of text and labeling them as falling into certain categories” (Joffe & Yardley, 2004, p. 59). The coding system is the heart of the content analytic method (Smith, 2000). The code represents an important meaning related to the researcher’s question (Braun & Clarke, 2006) and can be organized based on manifest or latent content of the data (Boyatzis, 2005; Joffe & Yardley, 2004). Manifest content refers to information that is directly observable and countable. For example, a researcher can choose to count how many times the students used the word “memory” within the data set. This approach does not consider the context in which the word is used. In order to understand the meaning of the particular word used by the students, the researcher

needs to look at the data on a latent level by considering underlying and implicit meanings (Boyatzis, 2005; Joffe & Yardley, 2004). In this study, latent themes were the primary focus for data analysis. The main goal was to understand the latent themes within the content of the medical students' journals written after an activity with a person with dementia, their mentor.

Two approaches to developing codes or themes are: inductive and deductive coding (Boyatzis, 1998; Braun & Clarke, 2006). Inductive coding, or a bottom-up approach, (Braun & Clarke, 2006) is a data driven approach and allows the researcher to analyze the data without a preconceived coding scheme. Deductive coding is a theoretically driven approach and begins with a theory or previous research results. It enables researchers to support, refute or elaborate prior findings and theoretical frameworks (Hsieh & Shannon, 2005; Joffe & Yardley, 2004). Similarly, "a 'theoretical' thematic analysis" (Braun & Clarke, p. 84) refers to a researcher-driven approach where the analysis is guided by the researcher's theoretical interest. In this study, an inductive approach was used in which codes and themes were identified based on the data rather than on preconceived categories.

### **Institutional Review Board Approval**

The program received Institutional Review Board approval from Northwestern University in 2005. All participants from 2005, students and persons with dementia have a signed informed consent on file, which they completed prior to program participation. For this portion of the overall study, a qualitative content analysis of 107 journals,

collected in years 2009-2012 was approved by the Loyola University Chicago Institutional Review Board.

### **Data Collection**

The data for content/thematic analysis was obtained from the Northwestern University approved study, The Buddy Program (IRB#STU00030632, Morhardt Principal Investigator [PI]). As previously described, students were paired with their mentor (person with dementia) in the Fall of each academic year. Program requirements requested students submit a semi-structured journal (see Appendix B) documenting their time with their mentor as soon as possible following their activity and submit to the program PI by e-mail. The semi-structured journal outline was as follows:

- 1) The date and time of the activity;
- 2) A statement of how they spent their time together;
- 3) A description of their 'buddy's' mood and behavior throughout the activity;
- 4) Student's reactions, thoughts and feelings during and following the activity;
- 5) Interactions with the caregiver, if any;
- 6) Any concerns that might have arisen during the activity; and
- 7) Their plan for the next visit.

Each student was assigned a subject identification number and each journal was labeled by subject number and date of activity (year.month.day, e.g. 501\_2009.10.5.) These data were kept in a password-protected file that was viewed only by the PI of this project and co-investigators on the parent project.

### **Sample Recruitment Procedures from the Original Study**

This is a secondary data analysis of narrative data collected during academic years 2009-10, 2010-11, and 2011-12. The sample from these three years was 27 students and 107 journal entries.

As part of the parent study, volunteer medical students were recruited from Northwestern University's first year medical school class in the Fall of each academic year. Recruitment included an e-mail announcement to all first year medical students describing the program and an invitation to a group lunch to discuss program requirements and expectations. The PI and program staff attended the student's 'Activities Fair' during orientation week, usually held every August. Interested students completed a program application and participated in a 20-30 minute interview with the PI and co-investigator, a clinical social worker in the Northwestern Cognitive Neurology and Alzheimer's Disease Center. The interviewers asked questions regarding the student's interest in the program, what they hoped to derive from the experience, any past experience with older adults and persons with dementia, their preliminary ideas for their career, and any foreseen time constraints. The program required students to commit five hours a month to the program: one hour in group-process meetings with the other medical students in the specific program year, and four hours in an activity with their mentor. Selected students to the program were notified by e-mail and underwent a three-hour orientation on Alzheimer's disease and related disorders, the impact of disease on the person and family and helpful communication strategies. Following the orientation, the students were 'matched' with their 'buddies' or mentors at a luncheon where they were



given time to get to know one another. At the match luncheon, students were provided a series of questions to ask the person with dementia and after a period allotted to their conversation, used these to introduce their mentor to others. In order to apprehend the students' experiences as soon as possible (preferably within 24 hours), the students were requested to submit a semi-structured journal as described earlier, to the researcher. (Refer to Buddy Program Manual in Appendix B for all recruitment procedures, student application, orientation schedule, mentor interview form, and student journal outline.)

### **Sample Description**

The medical students documented their experience with their mentor by submitting semi-structured journal entries provided by the researcher. Seventy-one first year medical students participated in the program from 2005-2012 and submitted 256 journal entries.

For the purposes of this study, a convenience sampling of narrative data gathered during years 2009-2012 was analyzed resulting in a sample of 27 students and 107 activity journals. These three years of data were selected due to the fact that they represented the most recent data set in the program's operation, benefiting from slight program modifications along the way to improve information gathering and research questions. For example, data included students' responses to questions regarding their experience with older adults and those with dementia and such variables as the number of hours students spent with their mentor. This information was not consistently captured prior to that time.

The purpose of qualitative data analysis was to obtain a more informative, richer and deeper understanding of the students' experience than what could be obtained from quantitative analysis. Medical student participants submitted semi-structured journals (see Appendix B) by e-mail to the researcher following each activity with their mentor. The sample size of 107 journal entries from 27 students was appropriate for this qualitative research study (Guest, Bunce & Johnson, 2006) and the researcher was able to achieve data saturation. Saturation is the point in data collection when no new or relevant information emerges (Given, 2008).

### **Sample Characteristics of Buddy Program 1997-2012**

The sample characteristics here are reported for the 27 individuals whose data were analyzed for the present study and the remaining 150 first year medical students who participated in the program prior to the period for which data were analyzed, that is 1997-2008 (see Table 1). This was done in order to provide a larger overview of the participants as a whole and to show that the sample for analysis was representative. An additional 17 non-medical students participated over the duration of the program and will not be discussed further as they represent other disciplines.

For the 27 participants whose data were used in the present study, mean age was 23 (SD=2), slightly over half were male (56%) and a large proportion (78%) were white, with 22% from different Asian groups. Seven percent were of Latino ethnicity. The mean level of education was 16 years. Fifty-six percent responded they had experience with persons with Alzheimer's or another dementia prior to their experience in the buddy program and 93% indicated they had experience with older adults mostly through a

relationship with a grandparent. Students submitted a mean total of four journals (SD=2) over the course of the academic year with a total mean of 18 hours (sd=8; range 11-30) in activity with their mentor over the program year.

Table 1. Sample Characteristics of Current Study 2009-2012 and Parent Study 1997-2012

Medical Student Program Participants		
	2009-2012 n=27	1997-2012 n=150
Age, years	23±2	22±2
Sex, % female	44	50
Race, % White	78	53
Race, % Asian	22	39
Race, % Black	0	3
Ethnicity, % Hispanic/Latino	7	7
Education, years	16	16
Experience with AD patients prior to program, % yes	56	
Experience with older adults prior to program, % yes	93	
Monthly interactions, total journals	4±2	4±3
Interactions, total hours	18±8	

### Method: Stages of Data Analysis

Three years of medical student journal entries were analyzed (see Table 2 for number of students and journals per year).

Table 2. Students and Journals by Year 2009-10, 2010-11, 2011-12

Year	Students	Total Journals
2009-10	N=7	N=29
2010-11	N=13	N=47
2011-12	N=7	N=31

The qualitative content/thematic analysis comprised several steps. The first step involved immersion, which required detailed familiarization with all of the data (Braun & Clarke, 2006). To complete this step, the entire text was read “in an active way” (p. 87); that is, interacting with the text while reading, annotating thoughts, reactions and highlighting key passages. The 107 journal entries were initially read three times over a period of one month and discussed with the dissertation chair.

Next, all of the journal data were entered into a qualitative data analysis software, QSR International’s NVivo 10, to manage and aid in the analysis of the data. As stated, all data were de-identified to protect the participants’ confidentiality and privacy. All computer files were kept in a password-protected computer and only the PI had access to the files.

Coding or categorizing the data into meaningful units (Miles & Huberman, 1994) was the next step. The basic coding process in content analysis is to organize large quantities of text into much fewer content categories (Weber, 1990). The first level of coding, what is called the condensation phase where preliminary units of coding are developed (Schreier, 2012) was where the PI made decisions on what was a meaningful unit of coding by considering the research question. According to Tesch (1990), such a text unit needs to be understandable by itself and carry one idea. Tesch further explains, “the text segments must be carved out of their context in such a way that they retain meaning, even when they are encountered outside of their context” (p. 119). Next, the PI developed a set of codes, which were then grouped into more general categories. This process of integration and “fusion involves the researcher thinking through what codes

can be grouped together into more powerful codes” (p. 62).

The process of this qualitative content analysis was iterative. Codes changed as some codes decayed or lost their meaning and others developed throughout the analysis (Miles & Huberman, 1994). In this study, the PI attempted to code data exclusively into just one category in order to develop codes and categories that were clearly defined (Joffe & Yardley, 2004) and took care to minimize the overlap between codes, so it would not be difficult to differentiate the various aspects of the content.

The coding of the data was reviewed repeatedly as a method to ensure the code reflected the words being coded. Specific topic areas were looked at repeatedly in both the original journal data and in the coding view of the individual codes. Codes were grouped together as common themes that aided in the analysis of the data. This was achieved through the use of nodes. NVivo uses the term nodes to provide a way to organize the data by codes and allow for hierarchical structure to be built in the platform. Nodes also act as a basket, a way to combine similar data. The term “references” refers to the number of times the material was coded in the data, and the term “sources” refers to the number of different documents where the references were found.

There are three types of nodes available in NVivo: free nodes, tree nodes and case nodes. Free nodes are a way to categorize data that are similar or reflect a trend, and to group data together until the researcher determines a pattern or hierarchy of information that would be helpful to show in order to better understand the data. Tree nodes are developed as one begins to see a relationship between the data emerge. Tree nodes impose a parent-child relationship, in effect, building a family tree that helps further

organize the data and serves as a tool in analysis. Case nodes in this project were used to house the demographic data of the individual participants. The attributes that defined each participant were housed in the case nodes.

### **Trustworthiness (Reliability and Validity)**

The establishment of rigor in quantitative methods is through internal and external validity and reliability (Merriam, 1995). Reliability and validity are “rooted in a quantitative positivist conception of research” (Schreier, 2012, p. 191). Internal validity asks whether the researcher is measuring or observing what s/he thinks s/he is measuring or observing; external validity addresses the ability to apply with confidence the study findings to other people and situations; that is, is the study generalizable. Qualitative researchers do not claim scientific objectivity (Warren & Karner, 2005); therefore, notions of validity and reliability need to be grounded in the worldview of qualitative research (Merriam, 1995). In qualitative research, reliability and validity are thought of as the trustworthiness of the procedures and data generated (Stiles, 1993). The concepts of credibility, dependability and transferability have been used to describe various aspects of trustworthiness (Guba, 1981; Lincoln & Guba, 1985; Patton, 2002).

Credibility deals with the focus of the research and refers to the confidence in how well data and processes of analysis address the intended focus. It is concerned with the extent to which the results of a study or a measure are repeatable in different circumstances (Lincoln & Guba, 1985). Choosing to analyze narrative data from 27 students allowed the PI to examine the research question from a variety of individual perspectives (Patton, 2002). The amount of data is also important in establishing

credibility and data saturation was achieved with this sample size.

Credibility of research findings also deals with how well categories and themes cover data, that is, in this study no relevant data have been inadvertently or systematically excluded nor have any irrelevant data been included. Credibility is also a question of how to judge the similarities within and differences between categories by showing representative quotations from the text. Seeking agreement among co-researchers, experts and participants is a way of establishing credibility. The PI discussed the coding and selected quotations with a colleague who assisted with program implementation as well as the dissertation committee chair, and both established agreement on the final codes.

Another aspect of trustworthiness is “dependability”. According to Lincoln and Guba (1985), dependability ‘seeks means for taking into account both factors of instability and factors of phenomenal or design induced changes’(p. 299), that is, the degree to which data change over time and alterations made in the researcher’s decisions during the analysis process. In the present study, all students were given the same semi-structured journal format. Judgments regarding similarities and differences of content were addressed by an open dialogue with the PI’s colleague and committee chair.

Trustworthiness also includes the question of transferability, which refers to the extent to which the findings can be transferred to other settings or groups. To facilitate transferability, it is important to give a clear and distinct description of culture and context, selection and characteristics of participants, data collection and process of analysis. A rich presentation of the findings together with appropriate quotations

enhances transferability. In qualitative research, trustworthiness of interpretations deals with establishing arguments of the most probable interpretations (Graneheim & Lundman, 2004).

The development of a good coding scheme is central to trustworthiness in research using content analysis (Hseih & Shannon, 2005). A potential threat to trustworthiness is research bias, arising out of selective coding of the data. While selectivity cannot be eliminated (LeCompte, 2000), it is important to be aware of how it affects data analysis as good qualitative data are as unbiased as possible.

The PI attempted to not presuppose her thoughts on the organization of the data, but rather let the organization emerge as the process of importing documents and coding each piece took place. The researcher recognized the difficulty limiting these presuppositions due to the length of time operating the ‘buddy program’ and previous cursory thematic analysis early on in the program. Still, the PI was open to what the data had to say and attempted to remain as objective as possible during the analysis while recognizing that subjectivity could not be entirely eliminated.

In a conventional content analysis, categories are derived from data during data analysis (Hseih & Shannon, 2005). Over the course of four months and eighteen time points (weekly) the PI checked the coding by applying established codes between each coding period. Miles and Huberman (1994) wrote, “although the coding will be influenced by similar subjective processes on both occasions, consistent coding by the researcher at least indicates that the distinctions made between codes are clear in the researcher’s mind” (p. 62). To further establish trustworthiness and to overcome



researcher bias in data interpretation, coded medical student journal data were sent to a colleague who assisted the PI with ‘buddy program’ facilitation during the three year period of data collection and who holds a master’s in social work. This established a form of inter-rater reliability (Weber, 1990). Schreier (2012) states, “Where the results of the two rounds of coding differ systematically, you will have to go over your coding frame again and revise it. Where the results of the two rounds of coding coincide, you can consider your coding frame to be reliable” (p. 34). The PI valued the dialogue with her committee chair and co-worker when developing and refining the thematic coding until there was agreement with the way the data were labeled and sorted.

Additionally, the researcher kept detailed notes on decisions made throughout data analysis using the computerized data analysis package NVivo 10 (QSR) to enhance trustworthiness (Roberts & Woods, 2000). DiGregorio and Davidson (2008) state, “Qualitative data software analysis can strengthen validity, but it is not, in and of itself, a guarantee that expectations for validity or trustworthiness have been met” (p. 51). However, the way NVivo organized the process and allowed for re-examination of the data, provided another mechanism that contributed to the trustworthiness of the project. An additional method used to address trustworthiness included seeking feedback from the PI’s dissertation committee chair independently to assist in reducing biases and any assumptions during data analysis.

The following are examples of revisions made over the coding period, taken from the PI’s notes. Initially, the PI coded ‘feelings of camaraderie’ or having something in common with their mentor and ‘feeling a sense of friendship’ as two separate codes and

after recognition of the similarity of these concepts collapsed them into one code. In addition to ‘feeling camaraderie/friendship’, further analysis revealed additional themes of ‘feeling enjoyment/fun’, being aware of communication, expressing discomfort, and ‘feeling increasing comfort over time’. The categories ‘feeling uncomfortable’ and ‘feeling awkward’ were also collapsed into one category ‘expressing discomfort’. The code ‘increasing comfort over time’ was also joined with the code ‘forgetting disease when with buddy’. It was recognized that all of these themes focused on the student’s description of their relationship. Therefore, the parent theme ‘focus on the relationship’ was formed.

The PI also originally coded students’ attention to emotional content of themselves and their thoughts on their mentor’s feelings into a code called ‘empathy’. After repeated reviews, empathy was more specifically defined as ‘the ability to sense their mentor’s emotions, coupled with the ability to imagine what their mentor might be thinking or feeling’ which separated these themes more distinctly. Descriptive references to emotional content regarding their mentor was placed in another code entitled ‘perceiving mentor’s mood’. These two codes were then grouped under the parent node ‘focus on the person’. Students’ reference to their feelings about their mentors’ symptoms was then coded as ‘emotional response to symptoms’. The students often spoke of their surprise at the many remaining capabilities of their mentor. What was defined as, ‘recognition of strengths’ was further defined and included the code ‘change in perspective’. The researcher then grouped these themes into the parent category or node of ‘awareness of (the students’ sense of) self’.

## CHAPTER FIVE

### RESULTS

A qualitative content thematic analysis of 107 medical student journals following an activity with their mentor yielded 679 total individual coded references with coded data coming from all 107 journals. Students submitted a mean of four journal entries (SD=2.0). The students spent an average of 18 hours (SD=8 )with their mentors over the course of the academic year; however, with wide variability around the mean.

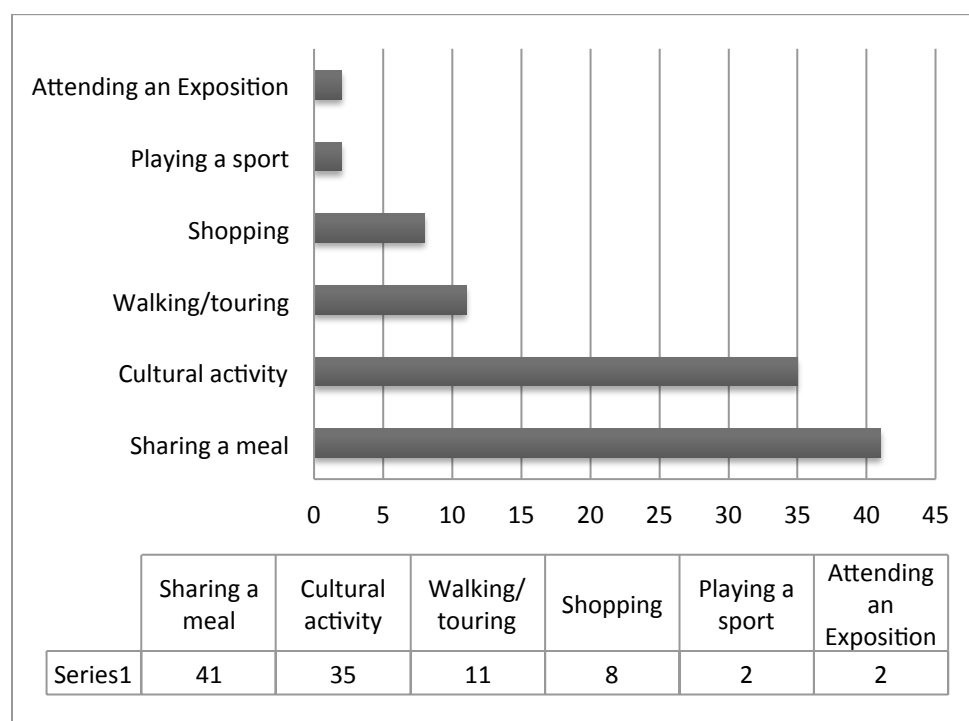
#### **Type and Frequency of Activity**

Activities are listed separately from the coding and were not analyzed beyond description (see Table 3). Most buddy pairs either shared a meal (38%) or enjoyed a cultural activity together (33%). Twenty-nine percent partook in several other types of activities such as walking and touring the city, engaging in a sport such as tennis, yoga or swimming or attending expositions such as the auto and boat shows.

#### **Thematic Results**

The analysis revealed a total of six major parent themes that were expressed recurrently with 12 child or sub-themes. These are listed and defined in Table 4 in order of descending frequency.

Table 3. Type and Frequency of Activity

Table 4. Student's Journal Themes, Number of Sources, Number of References, and Descriptions<sup>§</sup>

Theme	Sources	References	Description
<b>**SEEING BUDDY AS MENTOR</b>	32	47	<b>Students' descriptions of what they are learning from their buddy</b>
<b>**FOCUS ON RELATIONSHIP</b>	92	226	
*Feeling enjoyment-fun	56	73	Expressions of comfort, ease, enjoyment during the course of meeting with mentor
*Being aware of communication	35	44	Descriptions and reflections on how they were communicating and responding to their mentor
*Expressing discomfort	33	39	Expressions of apprehension, anxiety, discomfort
*Feeling increasing comfort over time	30	36	Student descriptions of increased feelings of comfort with their mentor over time. Includes forgetting about the disease when they are with their mentor.
*Feeling camaraderie-friendship	25	34	Feeling of mutuality or reciprocity, friendship, expressing commonalities – deeper than enjoyment or comfort

<b>**FOCUS ON THE PERSON</b>	<b>94</b>	<b>157</b>	
*Perceiving mentor's mood	94	143	Descriptions of their mentor's mood, perception of how the person was feeling.
*Feeling empathy toward mentor	11	14	The ability to sense their mentor's emotions, coupled with the ability to imagine what their mentor might be thinking or feeling.
<b>**FOCUS ON ILLNESS</b>	<b>64</b>	<b>124</b>	
*Recognizing mentor's symptoms - Memory - Visuospatial Abilities - Attention/Executive Function - Language	47	71	Objective reporting of observations regarding symptoms such as memory loss, repetition, word finding difficulty, motor (tremor, gait, balance) without expression of feeling or concern about it
*Expressing clinical concern-opinion	20	28	Expression of concern over mentor's living situation, safety, mood, behavior and opinion on what they needed to do.
*Expressing curiosity about disease symptoms	13	25	Students' expressions of curiosity regarding disease symptoms
<b>**AWARENESS OF SELF</b>	<b>36</b>	<b>65</b>	
*Experiencing a changing perspective/attitude	31	50	Students' recognition of a change in preconceived ideas of the person and/or the illness.
*Expressing own emotional response to mentor's symptoms	11	15	Expression of students' emotions in response to their mentors symptoms or situation
<b>**FOCUS ON THE CAREGIVER</b>	<b>50</b>	<b>60</b>	Students' documentation of their observation of and interaction with caregiver.

Note: The parent nodes are identified by a double asterisk\*\* (N=6) and child nodes are identified by a single asterisk\* (N=12). § References=679, Sources=368.

### Theme 1: Seeing Buddy as Mentor

The theme of 'seeing buddy as mentor' is particularly relevant due to the program's objective. The researcher looked for references from students regarding what they were learning from their mentor. Results revealed that 30% of the students (n=8) made 47 mentor-teacher references in 32 or 30% of the student journals; therefore a majority did not make reference to this theme directly. However, this theme does not refer to what the students may have learned from the mentor more covertly; that is, from

the relationship and experience. Table 5 shows excerpts representative of the mentor theme.

Table 5. Theme 1: Seeing Buddy as Mentor

<p><u>Chicago:</u> Descriptions of what they are learning about the city. Many of the students are not from Chicago while many of their mentors have lived in Chicago for many years and were eager to show the student their home-town. Students found that they were getting an introduction to the city, its history, from the vantage point of someone who had lived in the city for sometimes 60-70 years.</p>	
	<p><i>“Overall, it was great to hear about the city from (my mentor). (My mentor) told me where she grew up, how things were different in the area about 30 years ago. She pointed out many small details about her neighborhood and the stores around the area. Even small details about architecture and when buildings were put up.”</i> (503 2009.11.22)</p>
	<p><i>“(My mentor) told me a little about the history of the city and (his wife) told me a little about the architecture, especially about Frank Lloyd Wright.”</i> (606 2010.11)</p>
<p><u>Physician Mentor:</u> One medical student paired with a retired physician talked about how seriously his mentor was taking the mentoring role,</p>	
	<p><i>“I did notice that he often wanted to turn the conversation to talking about his work as a clinician. He is clearly very passionate about the work that he did and I think that he really misses it. At one point he even looked a little teary-eyed while he was talking about it. I think he is taking the role of being a mentor seriously because he tries to educate me about what he did as a physician every time we meet.”</i> (605 2011.1.15)</p>
<p><u>Art History:</u> Many of the mentors are very knowledgeable about art and a source of art education for the students, helping them to see things they might not have otherwise seen.</p>	
	<p><i>“It was interesting being there with (my mentor) because she was (or is) an artist. Especially when looking at some of the Gaugin’s.”</i> (504 2009.11.5)</p>
	<p><i>“(My mentor) is a wealth of knowledge about all art and I am thrilled to learn from him...I would like to go to more art museums with (my mentor) because I think he enjoys that and I don’t go on my own. I don’t feel like I get enough “culture” in medical school, so our art adventures are a wonderful break from science.”</i> (609 2010.12.05)</p>
	<p><i>“At the museum, I was happy to see that (my mentor) was enjoying herself and we got some kicks out of figuring out some of the figurines. (My mentor) made an astute observation about them that I had missed, and I was pleasantly surprised, not because I didn’t expect that of (my mentor), but the surprise you feel when you see something that you didn’t see before.”</i> (704 2012.1.28)</p>
	<p><i>“As we looked at the paintings, (my mentor) would direct me to go look at them very close up and then to stand back and watch how the painting changed. I think he really enjoyed teaching me about the art since I did not know much...When he would look at the paintings, he would notice very unique things and have interesting perspectives.”</i> (705 2012.1.8.)</p>

	<i>"I learned a great deal from (my mentor) about art and she made me see artwork in a new light...She noticed little things in paintings when I hadn't even thought to look." (706 2011.10.14)</i>
<u>Life:</u> A goal of the program is for students to better understand how persons with dementia are coping and living with their illness; however, persons with dementia also demonstrate how to live with the many transitions and losses they have experienced as in this student's excerpt:	
	<i>"I often wonder about how people transition through things in their lives that are such huge landmarks (marriage, divorce, etc), and (my mentor) really isn't afraid or sheepish about talking about any of it. I really like that about him, and I learn so much about so many things with him." (701 2011.12.16)</i>
<u>Civil Rights History:</u> This excerpt is from a student paired with an African American woman who had been very active in the civil rights movement and had many stories to share of the time and the people she knew and met. Many of this student's journals were filled with amazement at all he was learning first-hand from her.	
	<i>"Her stories about growing up and her time during the Civil Rights movement made me glad that I was given the privilege and gift to hear about her vast experience. Here I was standing with someone who had actually lived through the movement that I had studied so many times in school and had seen the fruit of in the opportunities my friends had as minority students. What a wonderful opportunity to hear first-hand about it! I'm excited for future visits to learn more from her experience." (704 2011.10.29)</i>
<u>Sports:</u> Although lower in frequency, there were some student-mentor pairs who participated in sports activities together. The researcher has known students to swim together; one pair did hot yoga. This pair played tennis and the student improved her tennis game as a result.	
	<i>"On the court, it quickly became apparent that (my mentor) was far better than me at tennis. Rather than have me struggle to keep up with him in a game, he immediately assumed a coaching role. This was really great to see because (my mentor) seemed very in his element. He has coached in the past and was even awarded state baseball coach of the year. As he instructed me on how to play tennis it was apparent why he won. He was patient and encouraging, and even though I was pretty bad at tennis, he made it fun." (705 2012.3.3)</i>

This theme of 'seeing buddy as mentor' reflects appreciation for the remaining skills and capacities in persons with dementia; that is, the ability to recall many events and facts from long ago. While they may not be able to balance a checkbook and are having trouble remembering recent events, the information that they have to teach their student is solidly within their grasp in their long-term memory, which is not affected by dementia in the early stages.

## **Theme 2: Focus on Relationship**

The theme ‘focus on the relationship’ was the most frequently coded theme. There were 226 references in 92 sources or 86% of the journals (N=107). This theme includes students’ expressions of enjoying their time with their mentor, experiencing common interests and developing a sense of friendship. However, some also expressed feeling discomfort at times particularly at the beginning of the relationship. For many, they experienced an increasing sense of comfort over the course of the year. Some students remarked on their increasing awareness of how they were communicating with their mentor and became cognizant of their language and the prejudices they brought to the experience.

### **2a: Feeling Enjoyment/Fun**

There were frequent expressions from students enjoying their time with their mentor. There were 73 references coded to the theme ‘feeling enjoyment/fun’ in 56 (52%) journal entries. As in the responses to the person’s emotional state, these brief statements captured an ease and comfort of being together. For example,

I had a really great time with (my mentor). She is very easy to talk to and a lot of fun (612\_2010.11.17)

I had a blast throughout the visit. We both really did enjoy our day together. We both just seemed to sincerely enjoy each other’s company and sharing our experiences and stories with one another. (502\_2009.11.20)

After we got to lunch and started talking, I found that we actually have a lot in common. I felt that she was comfortable with me and looking forward to future visits (601\_2010.11.9)

We just get along so well and have no trouble finding things to talk about. I wish I got to see her more often. (610\_2011.1.8)



Others gave lengthier descriptions. This student reflected on the ease of his engagement with his mentor very early on in the year.

We had an excellent conversation; it flowed very naturally and smoothly for the whole four hours. Judging from her body language and comments I think she was very comfortable with me and our interaction. (501\_2009.11.14)

Another student's early meeting with her mentor expressed relief at the ease and comfort she experienced:

Today I met (my mentor) at the Art Institute by the lions. She was there, waiting at the top of the steps...I made a bee-line towards her smiling, and she seemed to respond; she either recognized me or recognized my behavior. Either way, it was easier than I thought it would be and (my mentor) seemed genuinely happy to see me. (504\_2009.11.5)

This student reflects on her fondness for her mentor and her husband and the reciprocal nature of the relationship and growing friendship:

I had a splendid time at the outset! (My mentor and her husband) are both such warm people. Now that we've met a few times, (my mentor) remembers me very well and is always excited to see me. She even likes to chat with me on the phone a bit. I feel like an adopted granddaughter at times. They are both so interested in my life and my own family. (706\_2012.1.3)

This student expressed enjoyment of her mentor's humor and fun-loving nature:

She is really funny and we both spent a lot of time laughing. She loves to be outside and be active and I could tell she was happy to have someone to ride bikes with. The one time I thought for a second that she got angry at a car, it turned out that she was just yelling to them that she felt bad that they had to be stuck inside a car and not on bikes like us! (610\_2010.11.21)

Finally, this student expresses warmth toward her mentor, a feeling of general happiness and reflects on the reciprocal nature of their conversation:

As usual, I felt extremely comfortable throughout our interaction. (My mentor) is the sweetest individual. We had wonderful conversations about religion, politics, her background, as well as my future plans. (My mentor) has such a wonderful outlook on her diagnosis that she makes it hard to feel anything but happy around

her. (706\_2012.2.29)

## **2b: Being Aware of Communication**

The theme of ‘being aware of communication’ is defined as the students’ descriptions and reflections on how they are communicating and responding to their mentor. There were 44 references to this theme in 35 (33%) sources with a significant number of introspective comments on how the students are being challenged and what they are learning about themselves. One student frankly described her frustration at hearing her mentor repeat the same thing over and over, but expressed recognition of her own self-growth as a result of this challenge.

I must admit I have been getting a little frustrated in talking to (my mentor) at points. When she asks me the same question for the sixth or seventh time in two hours it can be a little tedious. I try very hard not to show this and I feel really bad when I get frustrated. Being a naturally very impatient person I think it has been good for me to go through this and try to be more understanding. (504\_2010.3.4)

One student made three distinct references to communication at different time points in the year. Early in the relationship she states:

I noticed during our conversation that it’s best to give (my mentor) some extra time to respond to questions. There were a few occasions where she answered a question with a very brief answer, but if I then waited a moment she then went on to share more with me. I assume that she needed a little more time to process and organize her thoughts. (601\_2010.11.30)

Then a month and a half later the same student remarked:

If I allowed for some silences and let (my mentor) process my comment, she usually ended up sharing a lot more information with me. I’ve learned if I’m really patient and allow the conversation to flow at a slower pace, then I can really get to know (my mentor) better. (601\_2011.1.15)

She then went on to talk about her ability to be more patient in this excerpt from her

journal near the end of her year:

“When (my mentor’s) telling a story there are a lot of long pauses, but I’ve gotten used to just waiting for her to continue rather than jumping in and interrupting”.  
(601\_2011.4.5)

Similarly, this student reflected:

I feel like my interactions with (my mentor) are becoming more fluid as I begin to ask fewer complex questions and incorporate his viewpoint into my own speech. I also feel more comfortable ‘jumping in’ when (my mentor) struggles for too long with a word or sentence without threatening his independence. Also, I have noticed that sometimes it becomes easier to relate to (my mentor) when I take time to say or ‘find’ the right word. (604\_2010.12.3)

This student is discovering a critical insight; that is, how her efforts to communicate well with her mentor make a difference in their relationship. Not only is she learning about the most skillful ways of communicating, she is developing a self-awareness regarding her overall contribution to how her mentor is experiencing the relationship. This supports personhood and the social construction of the self.

The following student commented on his communication style, but is unsure he is doing the right thing and used the journal to dialogue with the PI regarding this uncertainty. This demonstrates sensitivity and respect for his mentor, again supporting and acknowledging the ‘person’.

(My mentor) only showed evidence of memory loss a few times during our conversation. Each time, it initially caught me off guard because he was interacting so normally for the majority of the conversation. I answered his repeated questions each time, and did not challenge his repeated questioning. I was afraid if I challenged him to remember it would cause an awkward moment or anger him. Was this the proper way to handle this situation? (608\_2010.12.05)

Another student remarked on the challenges of communication with someone with aphasia symptoms, but also how much she has been able to overcome them:

I noticed that (my mentor) hardly ever uses specific nouns when she talks, which makes understanding what she is saying difficult at times, but I've been surprised how easy it is for me to follow her thought process the majority of the time. (610\_2010.11.21)

Finally, this MD/PhD student who is also completing work in a research laboratory in addition to medical school insightfully reflected on her response to a question her mentor posed to her about his illness:

At one point I was talking about neuronal death and I used the phrase, 'By the time you begin to show cognitive decline, you already have significant neuronal cell death'. As soon as I said it I felt really awkward because I meant the 'you' to be a person in general, but realized that it was applicable to (my mentor) and didn't know if he interpreted it that way. I've never talked about the science of AD to a person with AD before and it really made me question if the way I speak about the disease is too impersonal and cold. (705\_2012.1.8)

This student honestly discussed the feelings many clinicians (and friends) experience; how does one respond and when is it best to just listen and be affirming:

I noted this encounter as the first time (my mentor) brought up the issue of her diagnosis and what it meant to her voluntarily. I think I did not know how to best respond to her. All I did was just listening, and acknowledging the difficulty she is going through. I wish I could offer more than that. (611\_2010.12.4)

Overall, the experience of participating in the program allowed students to reflect on their communication style, to express self-doubt, and to recognize how distancing, but also how relationship-building, language can be. These students' earnest reflections convey an attempt to connect meaningfully with their mentor.

### **2c: Expressing Discomfort**

Not all of the interactions were positive or about feelings of enjoyment/fun. As in any relationship, particularly one that is new, there are natural feelings of anxiety and apprehension. While there was also increasing comfort in the relationship over time

(Theme 2d) there were 39 references in 33 sources or 31% of the journal data relating to feelings of discomfort, anxiety and apprehension. These results are significant and compelling as these uncomfortable and anxious feelings may contribute to negative attitudes that many young medical students hold toward persons with dementia if left unaddressed and without opportunity for personal reflection. The students' candid expression of these feelings in their journal writing allowed for this disclosure. Table 6 demonstrates this theme.

Table 6. Examples of Discomfort during Early Relationship Stage with Key Words

<i>"At first I was a bit nervous and wasn't sure if we would be able to find things to talk about or find something entertaining to do." (502_2009.11.20)</i>	<i>anxiety</i>
<i>"I was a little worried she wouldn't recognize me." (504_2009.11.20)</i>	<i>anxiety</i>
<i>"At the beginning of our visit I felt a little anxious, because I didn't know how (my mentor) would react to me or if we would have a good rapport." (601_2010.11.9)</i>	<i>anxiety</i>
<i>"Unfortunately, when the woman started asking about my relationship with (my mentor), I felt extremely awkward. I didn't know what would be an appropriate response. I had no clue if the people in (my mentor's) social circle know about his diagnosis. I just remained silent and let (his wife) explain. She did not mention Alzheimer's and gave a pretty unsatisfying answer to the woman, who looked at me for elaboration. I just smiled awkwardly until she left the conversation. I am still a little uncertain on how I should answer if asked about how I know (my mentor). If his wife had not been there, I'm not sure what I would have said." (705_2011.11.29)</i>	<i>awkward</i>  <i>uncertainty</i>
<i>"I felt a little uncertain of myself and whether (my mentor) really wanted me there because of ...how much she talked however I tried not to let it affect me (my reactions). (501_2010.1.9)</i>	<i>uncertainty</i>
<i>"I was very excited about finally being able to spend time with (my mentor). I was also a little scared that she was not going to remember who I was and as a result would act reserved with me." (602_2011.1.22)</i>	<i>apprehension</i>
<i>"In the beginning of the visit, I was mildly concerned about how (my mentor) and I were going to interact." (604_2011.1.22)</i>	<i>concern</i>
<i>"The trip with (my mentor) to the boat show was more difficult than I had imagined. At first, I wasn't sure how to interact with (my mentor). At times (my mentor) seemed perfectly normal and I felt like I didn't need to help him with anything. For example (in a previous visit) his son let him wander around the cafeteria and order on his own...there didn't seem to be any need for over and above assistance. However, during both our time at the boat show and our trip to the boat show, situations arose that required assistance and I wasn't sure how to respond." (607_2011.1.12)</i>	<i>uncertainty</i>  <i>uncertainty</i>

The feelings described in these quotes may parallel students' anxiety and apprehension when encountering a person with dementia in their practice. Does allowing an opportunity for reflection on the anxiety help to potentially ease it in future encounters? This early pre-clinical experience may prime the students for greater comfort during their clinical rotations.

## **2d: Feeling Increasing Comfort Over Time**

Students reflected on their increasing comfort in the relationship as they shared more information about themselves and got to know one another better. There were 36 references in 30 sources or 28% of the data focused on this theme. Representative examples of this theme are as follows, such as this direct statement:

I am definitely getting more and more comfortable with (my mentor).  
(602\_2011.3.8)

This student remarked on the increased sharing by her mentor of her family:

(My mentor) seems to be sharing a little more with me. I heard a lot more about her grandchildren and their medical conditions (which are actually pretty severe). I'm not sure if she told me more because that's where the conversation went or if she is starting to feel more comfortable around me. (504\_2010.1.29)

The following two students remarked on how their mentor's ability to be more open allowed him to feel a sense of ease in the relationship recognizing the growing mutuality in their relationship.

I felt like (my mentor) was able to be more open, and so that made me feel more open and at ease. (701\_2011.11.26)

(My mentor) has much to talk about and I loved hearing her stories. (My mentor) was also curious to hear about my life and my plans in medical school, so it was a very balanced and fun conversation. I definitely feel that our friendship is evolving. (503\_2010.1.3)

This student reflected on how much she was learning about the mentor's subjective experience:

I understand so much more about (my mentor's) experience than I could even imagine before we met. (610\_2010.11.21)

And, this student revealed his difficulty relating to older adults and the increasing ease he experienced getting to know his mentor.

It's very hard for me to be one on one with people, especially those that are older than me, but I'm finding it easier and easier to interact with (my mentor) which I really like. (701\_2011.10.8)

Within this theme of 'feeling increasing comfort over time' are students' comments on how they forget about the disease when they are with their mentor. One student remarked:

Our dinner conversation was incredibly varied, ranging from talking about Mohammed Ali to the Olympics to politics to the Republican candidates to abortion to culture. It was an incredibly convoluted and deep conversation, which happens to be the kind that I most enjoy. This was fantastic because it felt to me like (my mentor) was simply another good friend of mine talking about experiences and current events in a well-reasoned way. (704\_2012.2.25)

This student reflects mid-year a recognition that this experience is changing his perspective from one that focused on his mentor's symptoms to one where he forgets about the illness when with his mentor.

What I find most interesting about the museum experience reflecting about it is that we had such an enjoyable time that this became less about having a buddy program get together, and more sharing an experience with a friend. That is to say that I was not self-conscious or finding myself analyzing (my mentor's) behavior, but simply enjoying the time spent with her. I think that was an important step for me. I'm not her clinician, so I not only am untrained to analyze her behavior, but it's not my place to analyze her behavior. I can make observations if something changes, but otherwise my purpose is to continue to be her friend, her mentee. (704\_2012.1.28)

The above theme illustrates the achievement of the essential program goal of ‘heightening their awareness of skills and strengths that remain in people with cognitive impairment.’

## **2e: Feeling Camaraderie/Friendship**

Camaraderie and friendship are defined as feelings of mutual interests and discovery of commonalities. While students express positive statements of fun and enjoyment, expressions of camaraderie and friendship refer to a sharing of common interests with their mentor, a significant part of a developing friendship. There were 34 references in 25 sources or 23% of the journals.

An excerpt representing this theme include this student’s identification with his mentor:

We share a lot of the same interest (including ethnic food, shopping, and art) and although we are both fairly quiet we have sharp senses of humor. (601\_2010.11.9)

This student reflects on the mutual exchange they had in their visit and the reciprocity of their friendship:

After this meeting, I felt really excited to be paired up with (my mentor) because it seems like we have a lot to talk about and a lot to teach and learn from each other. (605\_2010.11.29)

This student remarks about his surprise at how the age difference does not matter:

With each visit, it continues to surprise me that even though there is such a big age difference between us and we have different backgrounds, we always have so much to talk about. (605\_2010.12.21)

These students and their mentors clearly have mutual interests:

I was excited when he told me about his affinity for motorcycles. (My mentor) commonly buys defective bikes, takes them apart, and then puts them back together. He said that this activity keeps him mentally fit. I suggested that one of



our activities in the future is to work on his bikes together since I have a degree in mechanical engineering, and he was receptive to this. (608\_2010.10.29)

Both she and I have had some experience with belly dancing, so there was a running commentary about how great the dancing was and our past experiences and how hard belly dancing is to do it well... (My mentor) loved being out 'at a club' and told the doorman when we got back about how great of a time we had. She also told me that she likes hanging out with me because she feels young again; I was elated to know that she had such a great time! (707\_2011.12.17)

This student/mentor pair related on an intellectual level that has created a bond between them that transcended the illness and gave the student a positive experience.

Through it all, it was like hanging out with an old friend, talking about experiences, thoughts about the world, and discussing his bookshelf (which I found had almost the exact same books as I. Huge Malcolm Gladwell fans!). I really felt like I got to know the person that (my mentor) was before his disease, as in his personality seemed less clouded by the diagnosis. It really lifted me up. (702\_2011.11.26)

Here is a mutual response to an exhibit at the Museum of Contemporary Art:

However, it soon became clear that (my mentor) didn't really get or like the modern art either. We had some laughs at the canvases that were just painted entirely one color and named after the color. (705\_2012.1.8)

Although at very different time points, the following two students expressed a feeling of closeness with their mentor and a sense of privilege for the experience.

Also, since going to the dog beach is part of (my mentor's) normal routine, it made me feel closer to him that he was comfortable including me in it. Even though we haven't known each other too long, it feels like we are old friends. (705\_2012.2.1)

One lady asked if I was (my mentor's) daughter. (My mentor) smiled and said No, but I wish she was and then said we were friends. It made me feel great to know that (my mentor) liked me so much. (707\_2011.10.16)

The above excerpts illustrate that for some of the students, they were able to engage in an intergenerational friendship where age and illness are forgotten and the reciprocal sharing of common interests and ideas are central.

### **Theme 3: Focus on the Person**

The students' expressions that revealed their 'focus on the person' made up the second most common theme. There were 157 references in 94 or 88% of the journals. These descriptions revealed their introspective perceptions on how their mentor was feeling. Some students took the step toward putting themselves in the 'shoes' of their mentor, attempting to understand how their mentor must feel regarding the changes they are experiencing.

#### **3a: Perceiving Mentor's Mood**

The theme 'sensitivity to emotion' is the students' description of their mentor's mood and their perception of how the person is feeling. This code was developed after several reviews of the data. The researcher originally coded all responses to the first question on the journal form – 'describe your mentor's mood', into one general category – 'mentor mood' which initially yielded 93 references. As additional codes emerged through further reading of the entire text, the researcher saw that the students were not merely describing their mentor's mood in response to the question, they were referencing a sensitivity to their mentor's emotional state throughout the content. Therefore, the 93 responses to mentor mood were re-coded yielding a total of 143 references to 'perceiving mentor's mood' in 94 sources.

The majority of statements were very similar. Students spoke of their mentor's positive mood; these were typically brief descriptions. For example,

(My mentor) was very upbeat and happy to see me (and) is usually a very happy and cheerful person. She was excited to talk, listen to my stories and is a generally funny person. (503\_2010.1.3)

(My mentor) seemed quite happy for our visit. (505\_2009.11.8)

(My mentor) was calm and cheerful. (601\_2010.11.30)

(My mentor) was very happy and as contented as always throughout our time together. (611\_2011.4.3)

(My mentor) was in a great mood during the visit. We spent a lot of time laughing together. (612\_2010.11.17)

These positive statements reflect a sense of positive engagement between the student and mentor and a mutuality of enjoyment of being in each other's company. This intergenerational relationship between a young medical student and older person with dementia is described in cheerful terms which may at first appear to be antithetical to what one might expect.

However, students' descriptions of what they perceived as their mentor's fear, frustration and discouragement were lengthier and included descriptions of their mentor's concern over the disease progression, such as, "(My mentor) is a little scared about what is happening" (504\_2009.11.5) and later in the year, this same student expressed,

In our walk, (my mentor) mentioned that the biggest thing she has had to get used to is doing things a lot more slowly and deliberately. I think she.... is getting somewhat frustrated by the extra effort required to maintain her lifestyle. (504\_2010.1.18)

This sensitivity to their mentor's mood and response to symptoms revealed the students' sensitivity to the emotional impact the illness can have on those living with the increasing challenges of this progressive disease.

Other statements (the first by the same student the following month) included:

I asked (my mentor) how she was doing and she said, 'okay. Just okay.' I think she has gotten lonely and said she was having a lot of trouble adjusting to not having a car. She leaves the house a lot less and I think this is starting to get to her. She also said she has been feeling differently lately. She described it as feeling like she was 'just here'. I took that to mean she had no real purpose; she had nothing to accomplish in a day and very few people to see. (504\_2010.2.18)

Again, the student went beyond simply naming the observed mood to thinking about the context for her mentor's expressions and to later reflect upon in her journal.

Similarly, another student recognized his mentor's change in mood as what appeared to be a response to his changing language abilities: "I noticed that later in the evening, he experienced increasing difficulty expressing his thoughts, and he began to appear a bit more discouraged" (604\_2010.11.6). This student was cognizant of how difficult it is to maintain cognitive abilities as his mentor tires over the course of the day and the effect this has on his mood as his mentor appears to have insight into these declining abilities.

Upon meeting his buddy for the first time on Match Day, this student described at length his mentor's description of his reactions to the diagnosis:

For the first 45 minutes of the meeting (my mentor) was in a very somber mood. He began by telling me why he was here. 54 weeks before (my mentor) was diagnosed with early onset Alzheimer's. Although it usually takes him a few minutes to recall a memory, he vividly remembers the day he was diagnosed. (My mentor) lost his license that day, and was at first frustrated by the rapid decline in his daily activity. He was no longer able to drive, lost his job, and is not very active anymore. (My mentor) is obviously very upset about his disease. He is

particularly frustrated by its rapid progression. I think he's also a little depressed because he has had to give up many of his former cherished activities.  
(608\_2010.10.29)

This student was able to hear first-hand a candid expression of the devastation and loss experienced by his mentor and to recount this story in his journal.

Another student observed her mentor's reactions to her symptoms of memory loss:

There were a couple of times when she would get frustrated about something that she couldn't remember or would get confused when she couldn't remember why she was doing or saying something. (612\_2011.1.8)

And, another student described an awareness of her mentor's mood without relating it to the illness:

(My mentor) was very subdued throughout the encounter. The dinner between (my mentor) and myself was a bit less natural than normal. (My mentor) seemed tired and not very talkative. (706\_2012.5.16)

Some students recognized the diversity in their mentor's emotional state over the course of the illness. This particular student recognized how the environment affected their mentor's mood and cognitive abilities:

Overall, (my mentor) was in a cheerful mood and was very interested in all the exhibits we saw. However, the aquarium was crowded and a little loud, so sometimes she seemed a bit anxious and distracted by all the commotion.  
(601\_2011.1.15)

This student remarked on how their mentor's mood changed as she experienced the symptoms:

(My mentor) went through several different moods throughout the visit. She was mostly very warm and friendly. Occasionally, after she would have a hard time remembering something, she would become frustrated and seemed angry with herself. (603\_2010.12.6)

Overall, the students were able to see the range of moods and emotions experienced by their mentors over the course of the year, again reinforcing the multidimensionality of living with cognitive impairment. They were able to recognize and describe the depth of responses such as joy, ambivalence, sadness and frustration experienced by individuals with Alzheimer's.

### **3b: Empathy**

The theme of 'empathy' is defined as 'the ability to sense their mentor's emotions, coupled with the ability to imagine what their mentor might be thinking or feeling'. These references were separate from their empathic responses regarding their interactions with the caregiver. There were 14 references in 11 sources or 10% of the data devoted to this theme. While many students were able to acknowledge and sense their mentor's emotions as described in the 'perceiving mentor's mood' theme, few actually imagined and articulated what it must be like to live with the changes. The following are excerpts of expressions of empathy from student journals.

She is very concerned that she's telling me the same thing again, which some of the time is true. She has a vague recollection that she's told it to someone but she's not sure who. I think this really bothers her and she mentioned that it has pretty severely impacted her friendships. I guess her good friends know she has Alzheimer's but she doesn't want to herald it to everyone so she's constantly afraid she's being repetitive. This must be especially hard at the art class she teaches; she hasn't told her students her condition and she thinks the relationship works fine but she suspects they have all guessed that she has memory loss. She also mentioned that things were easier since she lived alone, something I guess I can see. No one else depends on her remembering anything. Also, there is no one close enough to her that she would be constantly telling them the same things over and over. On the other hand, it sounds like she is a little scared about what is happening and it might be nice for her to have someone close to talk to. It must also be a little confusing for her to meet with me because she doesn't really know why I'm here. Today she thought I was a social worker. Despite that, she seems very happy to meet with me and seems to get something positive out of the time.

I hope I continue to be a positive force as I can imagine facing Alzheimer's would be an incredibly overwhelming task. (504\_2009.11.5)

This above reference is from a student who early on in the relationship attempted to imagine what it must be like for her mentor to experience memory loss and confusion and her desire to 'be a positive force' or to connect in such a way that this confusion can be relieved for a time.

Much later in the year, this same student continues to imagine what her mentor is experiencing:

The whole time we were walking she didn't know where we were going (she couldn't remember) but she never asked where I was taking her or got confused about where we were headed. Her trust in my lead and her flexibility to go wherever is pretty remarkable I think. I imagine it would be a very scary thing to not know so much about what is going on around you but to be game for an excursion anyway. (504\_2010.3.19)

This student is able to identify the frustration of living with memory loss and of losing and misplacing things early in their relationship:

I met (my mentor) outside her apartment and we walked over to the museum together. She was a bit late, because she couldn't find her coat. She seemed a little annoyed by this and spent a few minutes talking through where she may have left it. It really made me realize how frustrating it must be to find yourself having difficulty with normal daily tasks. (601\_2010.11.30)

Likewise, a mentor with word finding problems elicits this empathic response from her student buddy, also early on in the course of the relationship:

...that was just to illustrate that communication seems frustrating to her when she knows words in her head and can't get her body to say them. And of course it would be. I can't even imagine that. (610\_2010.11.21)

This student expresses a compassionate response to the threat the disease has to her mentor's autonomy and independence. It is as if the student senses her mentor's feeling of foreboding:

I do think that having Alzheimer's made (my mentor) a lot more sensitive towards these mistakes, and I could tell that she really wants to maintain her memory and function. I really felt for her. (611\_2011.1.6)

This student recognized the anxiety her mentor felt when unable to respond to the student's question regarding her schedule. While this example also illustrates a teaching moment for the student on communication skills that avoid inadvertently testing her mentor in this way, the student responds with a sense of how her mentor is feeling:

I had asked her what time her next meeting was and (my mentor) looked at me like she wasn't sure what I was talking about. Then she got kind of flustered because she couldn't remember the time and dug through her purse to take out her appointment book. As she was doing that she was telling me that she hates not remembering things like this – especially when she has always been so organized her entire life. I could tell that not remembering these things made (my mentor) very anxious. (612\_2010.11.17)

This student was paired with a person with primary progressive aphasia (a language based dementia) who worked as a docent for an art museum. While still very knowledgeable, the mentor's illness affected his ability to discuss the art in ways he was used to in the past. The student describes the empathic connection he made with his mentor in this way:

I could also feel his disappointment very palpably as he struggled through a tour that, according to his own account, he used to just be able to rattle off. We then went on a long lunch where we talked for a while...It is difficult for me to be with (my mentor) because I empathize tremendously with his difficulty. (703\_2011.11.13)



And this student was paired with a woman in her 50s and has this response: “I feel like it must be overwhelming to be diagnosed as young as (my mentor)” (705\_2011.11.1).

Finally, this student wonders what it must be like for his mentor to be in the position of not recognizing him and how the mentor’s memory loss affects the ability to form new trusting relationships. What a challenge for both student and mentor:

I was also a little surprised when he seemed like he didn’t know where he knew me from. It made me think that it must be hard for him to just have to trust me since he can’t remember how we know one another or why he is spending time with me. (705\_2012.3.3)

#### **Theme 4: Focus on the Illness**

The fourth major theme contained student’s reflections regarding the illness. There were 124 references in 64 sources to this theme. Sub-themes or child nodes were coded as 4a) Recognizing mentor’s symptoms (71 references in 47 sources); 4b) Expressing clinical concern/opinion (28 references in 20 sources); and 4c) Expressing curiosity about disease symptoms (25 references in 13 sources). What follows are definitions and representative quotes:

#### **4a: Recognizing Mentor’s Symptoms**

There were several references of students’ observations regarding a variety of cognitive and behavioral symptoms, possibly partially explained by the journal structure, which requested a ‘description of mentor’s mood and behavior’. It is also conceivable that being directed to provide this data allowed the student to pay careful attention to mood and behavior in a way that they may not have otherwise if not asked directly. The

result allowed the researcher to ascertain the students' awareness and understanding of their mentor's symptoms.

While the students received a lecture on dementia as part of their orientation to the buddy program, the relationship and interaction gave them an opportunity to understand how their mentor experiences the symptoms and lives with the illness. At the beginning of the program year, the PI described the different symptoms they may see in their mentor and that not all dementias present with memory loss in the early stages. For example, one student observed in the later part of the year: "I became again more cognizant of the extent of his disease and how it was affecting more than just his memory" (701\_2012.3.12). Additionally, students were informed that, while Alzheimer's disease is the most common dementia in older adults, it is not the only form of dementia.

The students made many observations of symptoms in their journal entries. As shown in Table 5, there were 71 references to the theme 'recognizing mentor's symptoms' in 47 journals or 44% of the sample. Students would also often bring observations of the symptoms they were seeing in their mentor along with questions regarding the disease to the monthly student process meetings. Depending on their interest, didactic educational lectures were provided at these meetings by clinical faculty (neurology and neuropsychology) and students were given the opportunity to share their experiences with their mentors among each other. The following entries reflect this theme and are separated by the observed symptom. Table 7 contains salient quotes regarding the students' observations of their mentors' memory loss.

Table 7. Recognizing Mentor's Symptoms: Memory Loss

<b>MEMORY</b>
<p>One student during the middle of the year described her observations:  <i>"I definitely noticed that (my mentor's) memory loss might be getting worse. She was more repetitive with her stories than usual."</i> (602_2011.2.15)</p>
<p>And the following week she observed:  <i>"She forgot that we had scheduled to meet, so when I got to her apartment, she was not there. I asked the front desk and they found out that she was in the activity room."</i> (602_2011.2.22)</p>
<p>Later in the year this same student continues to observe:  <i>"I keep noticing that (my mentor) tends to repeat the same stories every time that I visit"</i>. (602_2011.4.27)</p>
<p>Another student remarked early in the year the difference between short and long term memory abilities in his mentor.  <i>"I did notice some short-term memory issues in (my mentor), for example, she could not remember my name or where I had gone to college throughout the entire visit. She also repeated two stories she had told me. Overall it seemed that (my mentor) had more trouble remembering very recent things we had done or talked about. However, (my mentor) could remember more details about her past, the city, and her neighborhood."</i> (503_2009.11.22)</p>
<p>This student observed her mentor's difficulty remembering her or the reason for their meeting, in addition to his symptoms of language and memory and how he was coping with them:  <i>"He had to be reminded a few times who I was and why we were meeting. At times he would lose his train of thought or have trouble coming up with a word that he wanted to use, but then he would laugh at himself and take the time to come up with the word or idea."</i> (605_2010.11.29)</p>
<p>Early in the relationship, this student makes the following observations about his mentor's memory and an expression of concern regarding his mentor's memory for the time they are spending together:  <i>"Throughout our conversation I began to notice some signs of memory loss. For example, it took (my mentor) a little while to remember her buddy from last year. This made me wonder how much (my mentor) will be able to remember about me after this year. Also, there were a couple of instances where she asked me a question I had already answered."</i> (601_2010.11.9)</p>
<p>Later in the year this same student remarked on what she observed as progression from previous interactions:  <i>"I noticed during this visit that (my mentor) had a few more memory problems than she usually does. For example, she kept forgetting whether or not she had ordered soup and changing her mind about whether or not she wanted it, so she ended up confusing the waiter a little bit."</i> (601_2011.4.5)</p>
<p>Another student noted the short-term memory loss in this way:  <i>"Had a couple of occasions where we would talk for a good 30-40 minutes and then the next time we would talk I would have the same 30-40 minute conversation."</i> (606_2011.1)</p>
<p>Later he and his mentor's wife went to a play where his mentor was taking tickets and he observed his mentor struggling:  <i>"He had some trouble with his duties: his hands were shaking so badly that he took some time to tear the tickets. Then he would forget which part to give to people. Then he would forget where to put the ticket stub that he kept. Not that this happened for every person, but every now and again. (His wife) asked if I could help him out, but when I offered to help he was pretty firm about not needing help."</i> (606_2011.1)</p>

Another student described his observations of his short-term memory loss as such:

*“It has become much worse, and is starting to manifest in more and more. For instance, he asked me 4 times if I would like mayo with my sandwich. He also went through all the motions of putting his outside clothes on (we wanted to go for a walk because it was a warm day), but he kept asking what the weather was like. Then when he got his shoes on, he sat down on the couch and took them off, totally forgetting that we were going for a walk. Instead, we sat inside and chatted some more.”*  
(701\_2012.3.12)

The preceding quotes are representative of students’ recognition of their mentor’s memory loss, how it is affecting their lives, and how they are coping with it (with humor in some or a lack of awareness in others). In some instances, the student remarked on the effects of repetitive questions and forgetfulness on their conversation and interaction. Compared to other symptoms, memory loss is the most frequent symptom observed by the students. This is not surprising, due to the fact that the majority of the mentors had a diagnosis of Alzheimer’s type dementia, characterized primarily by early deficits in short term memory.

Other symptoms observed by students were changes in visuospatial ability reflected in the following excerpt (see Table 8):

Table 8. Recognizing Mentor’s Symptoms: Visuospatial Ability

<b>VISUOSPATIAL ABILITY</b>
<p>This student describes problems his mentor experienced with visuospatial processing in this way: <i>“(My mentor) seemed to have the most difficulty with numbers. He had a lot of trouble counting money (his wife said it might be a vision problem) and a lot of trouble with time. In the cab I saw (my mentor) look at all of the bills in his wallet several times (upwards of 20 bills I would say). He would start at the front of the pile and cycle through to the back, looking at each bill once. I wasn’t sure what he was looking for or what he was having difficulty with.”</i> (607_2011.1.12)</p>

This student appears to be struggling to understand why his mentor is having such difficulty with counting money. His mentor in fact struggles with impairment with predominately visuospatial abilities, and was not likely able to recognize each bill, how

much he had and what he was to pay. The student had not encountered this kind of situation and was not prepared for what to do. However, reflecting upon this in his journal allowed for him to bring this to the attention of the researcher and a discussion and education could take place.

Ultimately referring to their mentor's changes in attention and executive function, these students in Table 9 commented on their mentors' difficulty being in an over-stimulating environment.

Table 9. Recognizing Mentor's Symptoms: Attention/Executive Function

<b>ATTENTION/ EXECUTIVE FUNCTION</b>
<p>This student expressed awareness of the difficulty of sustained attention when the environment is overstimulating and the negative effects this can have on her mentor's functioning:</p> <p><i>"Since there were a lot of young kids running around the aquarium it was a little difficult to talk with (my mentor) and sometimes she seemed distracted. During this visit I noticed a few times where (my mentor) was having difficulty remembering words correctly. For example, a few times she had trouble remembering the name of the Field museum down the street."</i> (601 2011.1.15)</p>
<p>Similarly, this student described his mentor's response to an overstimulating environment and what appeared to be increased confusion:</p> <p><i>"One of the things I noticed at this visit is that he would often wander off from (his wife) and I, especially during the exhibit where it was kind of crowded."</i> (605 2010.12.21)</p>
<p>The inability for the mentor to inhibit responses as a result of another overactive setting was relayed by yet another student:</p> <p><i>"Being in a more crowded location definitely gave me a little more insight into how such situations can be difficult for (my mentor). For example, we first went into a smaller, more crowded restaurant that (my mentor and her husband) decided was too loud and would be distracting for her while she was trying to converse with us over a meal. Then also she kept catching movements out of the corner of her eye (like someone walking by our table) and reflexively jumping back a little like something was flying in her face." She was very open about discussing these things though, which helped me understand them.</i>" (610 2011.1.18)</p>

Some students remarked on the changes in language they observed in their mentor in Table 10.

Table 10. Recognizing Mentor's Symptoms: Language

LANGUAGE
<p>This student, paired with a person with the language based dementia of primary progressive aphasia, observed:</p> <p><i>“Throughout our encounter, (my mentor) struggled to communicate in nearly each of his intended sentences and easily gave up on thoughts he wanted to express. Sitting down one-on-one at lunch alleviated some of this difficulty, but his speech appeared significantly more laborious than compared with our previous visits.” (604_2011.1.22)</i></p>
<p>And another student observed:</p> <p><i>“I noticed, more this time than last, that (my mentor) is having a hard time putting her thoughts into words.” (612_2011.1.8)</i></p>

On the other hand, some students remarked how little they noticed the symptoms:

The only time at which Alzheimer's made itself known was at the conclusion of our visit, when she could not remember which door of the apartment was the exit. (506\_2009.12.5)

and one remarked,

I didn't notice any major signs of progression of Alzheimer's. (507\_2010.2.21)

Another observed only subtle changes,

It really is very rarely that I notice things, though I've started to pick that the timelines and events of some of his repeated stories or some of the events he's mentioned change a little. (701\_2011.12.16)

These excerpts demonstrate that students were able to reflect on the diverse neurocognitive symptoms they observed. They shared these differences in their monthly process meetings, ultimately giving each other a multidimensional approach to understanding dementing illnesses and a recognition of the diversity of experiences.

#### **4b: Expressing Clinical Concern/Opinion**

A theme that arose in 19% of the sample (N=20 journal entries, 28 references) was the expression of the students' 'clinical concern and opinion'. It was as if the students could not help but put on their clinical cap when reflecting on their time with

their mentor and provide their thoughts and recommendations from the perspective of a 'doctor'. Furthermore, many of the following excerpts reveal the students' understanding of how their mentor is affecting and being affected by the environmental issues of safety, support, meaningful activity, and potential isolation. For example, one student expressed her worry and opinion regarding her mentor in the following way:

When we met after the meeting she asked if we should go to lunch and I said that I had already eaten (it was 2:30) but would be happy to go to lunch if she hadn't eaten. She said she couldn't quite remember but she wasn't hungry. I was a little bit worried by this as I think it's a bad sign if she starts missing meals, considering she looks like she needs to eat on a regular basis. (504\_2010.4.7)

This same student also remarked on her safety concerns for her mentor during the same entry:

She also talked about sometimes when she was bored she would jump on the bus and go somewhere new to explore. I think she really enjoys this and is currently able to do it but I remember the time she got lost looking for me so I think if her status deteriorates anymore it might become a little unsafe for her to be gallivanting around town. (504\_2010.4.7)

Another student expressed her concern regarding her mentor's driving and his physical and functional abilities:

Right now, my big concern is how (my mentor) gets around, and what his physical capabilities are. On top of that, I'm wondering how much longer he should be able to drive (if he should be now). It just seems like he gets confused every now and again, and the reaction time isn't what it used to be, and I really do wonder how safe it is for him to drive. (602\_2011.3.9)

The next two students expressed particular concern regarding medications and their desire to be of assistance to their mentors:

I am concerned with (my mentor) receiving all of her medication. She has a little electronic machine that is supposed to remind her but she dismisses it every time it directs her to take something and becomes defensive when I offer to help. (Her

daughter) told me there are caregivers that come at night to remind her to take the medicine, I just hope they actually see her doing so. (501\_2010.3.8)

This student also took on the role of a concerned colleague by ‘reporting’ his concerns about his mentor:

(My mentor’s) panic attacks do not seem well-controlled and it might be worthwhile for someone to be in contact with her about seeking further treatment to alleviate the panic attacks, which seem to be disrupting her life substantially. I became aware this visit from talking with (my mentor’s husband) that she has been prescribed a series of SSRI’s to control some mood disorder, to little salutary effect....it might be worthwhile to evaluate (my mentor) for depression. She seemed very pessimistic throughout the visit, saying that too many difficult things were going on at once and asking not to talk further, lest a panic attack be precipitated. I hope this account is sufficient for the purposes of your office, but please feel free to call at any time for further clarification. (506\_2010.1.23)

Some of the mentors lived alone and this student wrestled with his mentor’s increasing isolation. He had an opinion on what his mentor should do and expresses frustration that she is not doing what he feels is best for her.

She is thoroughly and deeply hoping and praying that it does not get worse. To that extent, she does not want to talk or even think about the future possibilities of her disease progressing. I feel torn about this. On the one hand, it is understandable to not want to face with the possibilities, especially since they are only possibilities and not realities. On the other, I’m concerned about what her concerns are doing to her now and what they will do if, in fact, she does get worse. What do I mean? She informed me that she has stopped attending the (support) group. One big reason was time commitment, as she has all sorts of other medical problems that require multiple doctor appointments per week. However, it seems that the main reason is because other participants who are further progressed force her to face those possibilities. She has also informed me that she has had social interactions with neighbors and people at church, but that she has increasingly become more solitary. I can’t help but feel concern about the above tension she’s in. I understand the need for solitude, but I’m concerned about an imbalance between solitude and social interaction. There are things that allay this concern. For one, her interactions with me in the program and with people while she’s out with me have not changed. Also, I’m glad that she still has frequent interaction with her son and granddaughter. She speaks with great fondness about volunteering at her granddaughter’s school. (704\_2012.2.25)



While the students were given instructions that their relationship with their mentor was non-clinical, as demonstrated in the preceding statement, there was a natural inclination to express ‘clinical’ observations when with their mentor, especially with the knowledge that their mentor had a neurodegenerative illness. Hence, students were able to identify the symptoms and although students were not ‘treating’ their mentors, they were able to identify possible ideas of what might be helpful.

#### **4c: Expressing Curiosity About Disease Symptoms**

Students’ inquisitive statements and questions regarding how the memory loss and other cognitive symptoms were expressed in their mentor were coded as ‘expressing curiosity about disease symptoms’. There were 25 references in 13 (12%) of the sources.

For example one student made thoughtful observations regarding her mentor’s symptoms with appropriate questions that reflected an eagerness to probe for further understanding of what is causing these symptoms to occur in these ways.

While perusing the museum I thought an interesting contradiction of her memory loss came up. She couldn’t remember which rooms we had just come from so I was guiding us along. However, when we entered the Caravaggio room she commented on how the pictures had been rearranged since the last time she was here. I imagine the last time wasn’t that long ago and it strikes me as odd that she could remember that level of detail even though it was a pretty recent memory compared to not knowing which room we had just left. It is also interesting which details about me she remembers. When we first got to the museum she asked me if I had been before, and if so which parts I had seen. In response, I told her I had seen some of the impressionists. She remembered this tidbit and mentioned it at least twice after that point. On the other hand, when we were nearing the end of our time at the museum and then twice again within ten minutes, she asked me how much time I had to spend with her that afternoon. I’m not sure if the fact that we had been together for an hour so her memory was somehow ‘fatiguing’ (I don’t know if this actually happens) or the nature of the information made a difference, or if it’s completely arbitrary which things she remembers and which she does not. (504\_2009.11.4)

The same student continued to muse on her curiosity regarding puzzling brain function throughout a number of her journals. Later that year she stated:

I also thought it was interesting that (my mentor) did not remember that I was coming. I had called her the day before, although she had been distracted when I called since she was getting off a bus. She had also written down that I was visiting in her daily planner (I saw it when we were scheduling our next meeting). Maybe she doesn't look at her planner very much since there isn't too much written for any given week. When I got there she also knew she wanted to go downtown but couldn't remember why exactly (it turns out she had something she wanted to take back to Macy's). I would have thought my visit, which she clearly enjoys, would have stuck in her mind as much as her trip downtown to Macy's. Clearly it did not. Is this because they are different kinds of memories somehow or is it because one was imposed on her (my visit) while the other was something she thought up that she had to do for her own good (return a defective product). Is there some kind of agency related to what things stick? (My mentor) perhaps saw that I was coming and didn't remember because she knew I would come regardless whereas that Macy's product would not return itself. I don't know if that's at all how these things work but it is interesting what things stick in (my mentor's) mind and what do not. (504\_2010.3.19)

This student expressed a curiosity regarding her mentor's memory loss and wrote an intriguing reflection of her questions about what she observed. Putting herself in a clinical role would not allow for this kind of depth of understanding of how someone is living with these cognitive changes and the effects they are having on her life.

Another student similarly observed:

I was amazed at the way in which Alzheimer's could so selectively affect some neural pathways (how to get out of the apartment) and yet leave some others untouched (the lives of her children and their current occupations, for example). (506\_2009.12.5)

And this student wrote about her curiosity by reflecting on the confusion between normal age related memory loss and that due to a disease process:

I was very interested in what she remembered and what she didn't. A lot of things that she forgot about were minute things and I could not decide if it was due to the Alzheimer's or due to age. For example, she forgot that we visited a

certain room in the museum already, but when we set foot in there, she recalled. Other forgetful events occurred. She could not remember that I wasn't a member of the MCA and that was why we were lining up to get tickets. She had also forgotten, after about half an hour after I told her, that I had not eaten lunch. She again asked for my number. This is the third time she asked for it. I wrote it down in her address book for her. (507\_2010.1.10)

This student used her journal to ask the PI a question, desiring to learn more about the phenomenon she observed in her mentor.

I think (my mentor) is not recalling more of what we had just talked about than before. I understand this as a natural progression of her memory deterioration. Is it the case that the most short-term memories tend to be the ones most affected first? (611\_2011.4.3)

Overall, the students' focus and curiosity regarding their mentor's illness and associated symptoms, reflects their position as medical students and students of disease. It is not surprising that they would focus on symptoms that they observe and have a curiosity and opinion about those observations. However, the results demonstrate that while their attunement to their mentor's symptoms were part of their experience, it was, in fact, only part of it.

### **Theme 5: Awareness of Self**

The fifth major theme the researcher identified was the students' reflections on their own internal thought process and emotional reactions to their mentor and the time they were spending together. There were 65 references in 36 sources or 36% of the journals. This theme was then divided into the child nodes of 'expressing a changing perspective/attitude' and 'expressing their own emotional response to their mentor's symptoms'.

### **5a: Expressing a Changing Perspective/Attitude**

Reflected 50 times in 29% (N=31) of the journal entries were expressions of a ‘changing perspective/attitude’ or students’ recognition of a change in preconceived ideas of the person and/or the illness as a result of this experience. These reflections tended to describe positive aspects of their experience of the person with the illness and their caregivers in comparison to the images of Alzheimer’s they brought with them to the experience.

One student shared his changing perspective in this way:

At the beginning of the visit I was pleasantly surprised by how friendly and well aware (my mentor) was. Considering her age and recent diagnosis with MCI (mild cognitive impairment), I expected her to have a more difficult time maintaining long conversations. I was absolutely wrong...at no time did she demonstrate any problems communicating in any capacity and conveyed her emotions quite clearly. (501\_2009.11.14)

Another student remarked,

I originally thought it would be a lot more different and that (my mentor) would not be as aware and in control of his thoughts and ideas, but I could not have been more mistaken. (502\_2010.1.21)

Another student provided this lengthy reflection on his preconceptions,

I was quite frankly surprised when “my mentor” had gotten our 12/10 outing mixed up with the previous weekend. When I found out, I immediately jumped to the conclusion that her condition had caused the mix-up. After the conversation, though, I felt that my initial judgment was unfair; I’ve made the same mistake in the past. The same goes for when I forget a word or an event. Am I simply jumping to conclusions about whether what I’m observing is normal behavior or if it’s caused by whatever is going on in her brain? I really don’t know, mostly because I do not have the clinical expertise. I think the lesson I’ve learned from here is that, until I gain the clinical expertise, I should focus less on labeling behavior and more on (my mentor). The focus should be continuing to get to know her and helping her achieve her goals of remaining independent as long as possible, but also helping her cope with any changes that occur along the way. (704\_2011.12.15)

Similarly, this student remarked about her buddy,

At one point when we were walking back, (my mentor) jaywalked across the street when we didn't have the right of way. We held up some cars trying to turn. At first I wondered if it was a symptom of Alzheimer's, but then sort of felt guilty for thinking that. It seemed weird that I would assume his jaywalking was caused by the disease, when I jaywalk all the time myself. (705\_2011.11.1)

The same student two months later described this situation,

While we were chatting outside the coffee shop, (my mentor) accidentally let go of Buster's leash and he ran off to chase a bird. I chased him down before he could get far, but the incident once again brought up the dilemma of me assuming things are because of AD when they are actually pretty normal. After it happened, I thought to myself, (my mentor) must have forgotten he was holding onto the leash. But it isn't uncommon that Buster pull his leash out of my own hands, so it seems silly to think of it as pathological. I think it must be weird, especially at the early stages of AD, to distinguish what is normal absentmindedness and what isn't. (705\_2012.1.8)

Another student focused on strengths and provided an explanation for her mentor's capacity,

Initially I thought there was more cognitive decline, but after spending a little time with her I don't think that is the case. I get the feeling that she spends a lot of time alone without people to talk to, and I think she gets 'rusty' in her mental ability. The longer I stayed and talked to her, the better she seemed to be. (707\_2012.4.22)

Another student reflects,

I am surprised because I had almost forgotten already that she had Alzheimer's, and I was meeting her as part of the Buddy program. This person, really? (702\_2011.10.18)

In addition to these excerpts, the researcher observed throughout the data that the students consistently used the words 'amazed', 'impressed' and 'surprised' in response to their interaction with their buddy. Examples of these statements include:

I was amazed at how active he was for his age (502\_2009.11.20); I was very impressed that he was able to walk around the auto show venue for so long

(502\_2010.2.18); I was surprised to see how knowledgeable (my mentor) was (503\_2009.11.22)

and

I was really impressed with (my mentor's) mechanisms of compensating for his memory loss. (697\_2011.1.12).

These reflections reveal a key component of the buddy program. Students saw how their mentors continued to maintain an active lifestyle and live with their changing abilities, the antithesis of the stereotypes that they perhaps unknowingly brought with them to the program. This qualitative analysis reveals this attitudinal change in a way that a more quantitative questionnaire may not have captured.

### **5b: Expressing Own Emotional Response to Symptoms**

Although not as frequent as the changing perspective/attitude subtheme, students expressed an 'emotional response to symptoms'. There were 15 references in 11 sources or 10% of the journal entries. The students used words like 'hard to watch', 'sad', 'scared' and 'troubled' to describe their feelings. The following table of excerpts (see Table 11) illustrates this theme and begins with one student eloquently expressing his thoughts upon this first meeting with his mentor over a meal.

### **Theme 6: Focus on the Caregiver**

The sixth and final theme, 'focus on the caregiver', included expressions about the students' interactions with and observations of the caregiver. Sixty references were made in 50 journals primarily in response to the directive, 'Describe any interactions with the caregiver'. The majority of the interactions with the caregiver, 27 or 45% were

references to how the caregiver played a coordinating role in the interaction between student and mentor. These included scheduling the activity, for example,

We set up a tennis date for during the day on Tuesday, but (my mentor's wife) cancelled on Sunday because the weather forecast was grim. She then invited me to come to the lecture they were attending Tuesday night. (705\_2011.11.29)

Table 11. Examples of Students' Emotional Responses to Mentor's Symptoms

<p><i>"This is sweet and terrifying. (My mentor) is well-spoken, pretty, kind and yet something is eating away at her mind. She handles it with grace, smiles, asks me to pass the rice, tells me more, laughs. I still don't know how to feel. I am happy that I got to meet her and spend time with her, yes, excited to learn more about her life...and yet I am scared, do not want to see her start forgetting basic things (especially when she seems so all together right now), do not want to see (and can't bring myself to believe) that the (mentor) I met will change in any way other than normal over the course of this year."</i> (702_2011.10.18)</p>	<p><i>feeling puzzled</i></p> <p><i>feeling scared</i></p> <p><i>feeling hopeful things don't get worse or feeling anxious?</i></p>
<p><i>"It is hard to watch her struggle to recall memories she knows she should be able to recall."</i> (603_2010.12.6)</p>	<p><i>feeling unease</i></p>
<p><i>"Sometimes it was hard for me, emotionally, to see (my mentor) struggle with tasks or finding words. Up until now I hadn't seen any of his 'symptoms' other than an occasional lost thought or word."</i> (607_2011.1.12)</p>	<p><i>feeling unease</i></p>
<p><i>"It's getting more and more difficult for me to see him slip further, but I tend not to show it or let it affect me as much because he seems to take so much of it in stride."</i> (701_2012.3.12)</p>	<p><i>concealing troubling emotions</i></p>
<p><i>"I found this very sad, as it was the first time I'd seen (my mentor) exhibit the behaviors I've seen in my grandparents, who have more severe dementia. It sharply contrasted how normal (my mentor) seemed during our last meeting and drew attention to the progressive nature of the disease. While I doubt that his condition really changed much in the last month, it made me sad to anticipate the changes that we might see over this whole year."</i> (705_2011.11.29)</p>	<p><i>feeling sad</i></p> <p><i>feeling ambiguity</i></p>
<p><i>"I'm excited for future visits to learn more from her experience, but I am also troubled by the uncertainty of her clinical course and what her future difficulties might be."</i> 704_2011.10.29)</p>	<p><i>feeling sense of ambiguity</i></p>
<p><i>"I felt very downcast at her decline. I care about (my mentor) very much and it's hard to see her memory decline."</i> (706_2012.5.16)</p>	<p><i>feeling sad</i></p>

Several responses were simple statements about seeing or speaking with their mentor's caregiver such as

I had extensive interactions with (my mentor's husband) during the visit. My interactions with (him) have, to this point, been similar to those with (my mentor) – cordial and conversational. (506\_2009.12.5)

These students referred to how the caregiver helped facilitate conversation with their mentors,

I've spoken with (my mentor's son) several times as we set up our visit. He was also present for the first hour of my visit. He is very friendly and helpful, and both (my mentor) and I enjoyed talking to him. He helped facilitate some conversation and helped me learn more about (my mentor) so I could ask her more about herself after he left. (603\_2010.12.6)

and

(My mentor's wife) is great. She keeps the conversation going when she thinks of something that (my mentor) can tell me. (606\_2010.11)

Another student found the caregiver to be helpful in easing communication but was observant of the interaction between his mentor and his wife and his mentor's assertion of independence and autonomy:

(My mentor's wife) is his caregiver. She was very friendly and seemed very excited that (my mentor) is in the program. She let (my mentor) and I talk, but was able to fill in when he could not remember something, so that was really helpful for me to understand what he was talking about...at one point when his wife tried to help him come up with a word, (my mentor) made it clear that he wanted to come up with it on his own. (605\_2010.11.29)

Similar references were then coded as 'awareness of illness impact on family relationships'. In fact, 22% (N=13) of the references were observations of how the symptoms impacted the family relationships.

Students were able to witness first-hand how their mentors' families were struggling with the care of the person with dementia. Students made several references to their mentors' relationship with others particularly their caregivers, recognizing the



complexity of this relationship and how the historical and current interactions affect both the individual and the dyad.

For example,

I think (my mentor and her husband) used to have a dynamic where they would interrupt each other while the other was talking – which normally isn't a problem when the person can remember the original train of thought. (My mentor's husband) turned to me halfway through the night and said that he needs to be more mindful about doing that. (My mentor's husband) has started smoking again having quit for several years. He said that he's unsure why he started up again, but he left several times to smoke during the visit. It's a cause of stress for (my mentor) and she mentioned it several times to me...I also noticed that (my mentor and her husband) were fighting a lot more than the first visit. I am not sure if that is a normal dynamic of their relationship that is just coming out because they are in their natural environment or if it's something that is getting worse as time passes. (612\_2011.1.8)

For example, here is a student's documentation and view of the family dynamic.

This student had the opportunity to attend the Rita Hayworth Gala, the annual benefit for the Alzheimer's Association with her mentor, her mentor's daughter and son-in-law. At one point she spoke to the family when her mentor was not present and had this empathic and poignant response:

I enjoyed spending a little time with (my mentor's) daughter and her husband. I talked to both of them individually a little bit about (my mentor). The son-in-law's perspective was that (my mentor's) daughters probably weren't as concerned as they should be, but he was also a little hesitant to take on more responsibility for her. He also said he's noticed a big change in her since what she used to be. His description was that the last time she was at his house 'she might as well have been a chair' because she was quiet and basically had no interaction with the family. He said she's not at all the person she used to be. It was also interesting that he said his wife and her sisters get annoyed with (my mentor) over little things, like her always asking for (his wife's) number because she thinks she doesn't have it. His reaction was that they should save this frustration for situations, which are more potentially dangerous, such as (my mentor) getting lost. However, I wonder if (my mentor's daughter's) reaction might not be one towards the phone numbers rather a sadness at losing her mother.

This student went on to say

(My mentor's daughter's) view, from what I got from her, was definitely not as extreme. I don't know if this is because she's in denial or just sees her mother differently. (My mentor's daughter) said that on her good days, (my mentor) was basically how she used to be, but not so much on her worse days. She also told me about her youngest son, who showed an interest in art and who (my mentor) kind of took under her wing. I guess that relationship has fallen off a lot, probably due to (my mentor's) Alzheimer's and her son's growing up. (My mentor) usually makes little stabs at the fact that she no longer has a car, citing (my mentor's daughter) as a reason. I asked about that and (my mentor's daughter) laughed. Apparently (my mentor) has a good friend who happened to move in next door to her and it was actually him who found someone to buy the car and facilitated its removal. I was not surprised by this, considering (son in law's) comments about (my mentor's daughter) not wanting to interfere too much. I guess it's good that (my mentor) has a good friend near by who's looking after her however I think it might make it harder when the family has to take a larger role in caregiving. I also think that (my mentor's daughter) is in a position where she doesn't know what (my mentor) needs and isn't sure she has the time to provide the help. She mentioned she would have liked to go to the early-stage caregiver group but it wasn't very practical since she lives an hour away and it would conflict with when her kids were getting home from school. It will be interesting to see what happens when (my mentor's) condition deteriorates a little more because being a stay at home mom, I think (my mentor's daughter) could be a caregiver for (my mentor) if she were to move in. However after all the time I've spent with (my mentor), it seems like she is very proud of living in the city and is protective of her independence. This could be a major stumbling block for both of them in the future. (504\_2010.5.9)

The above journal entry is a lengthy reflection of the intergenerational family dynamic and how the family's response affects the person with Alzheimer's and each other. The student related her observation of the family interaction and recognized in her reflection how important the caregiving family is to the health and well being of the person with dementia over time. The student was also sensitive to the struggle the family experiences as they attempt to adapt to her mentor's increased dependency. She hears the difference in opinion and judgment that can be made from one family member toward another regarding what they believe is the better way to provide care. The student then

reflected on the struggles the family may face in the future. For this student, who had not met any of her mentor's family during the year in the program, this understanding of the family context provided her with a new and different lens with which to view her mentor.

Eighteen percent (N=11) of the references in this theme included reflections on students' understanding of the stress of being a caregiver for a person with dementia. For example, in the following quote, the student describes her reactions to the caregiver's story, expressing value for her perspective and recognition of the difficulty she faces in the caregiver role.

(My mentor) went to the bathroom right when they arrived, so (my mentor's wife) told me what had been going on... for the last four or five weeks everything had been really good. He (my mentor) had been really calm. Then last night they went out for dinner and when they got back, he started acting suspicious and on edge. However, this morning he was back to being calm. From my perspective as a medical student, it is really interesting to hear about the disease from her perspective. From my other perspective as someone who has had a family member with Alzheimer's, I really sympathize with how hard it must be for her to care for him daily, never knowing how he will be each day. (605\_2011.1.15)

This student reported his interaction with his mentor's wife recognizing the feelings of stress and burden she is experiencing:

At the end of the visit, (my mentor's wife) was telling me that it is just hard to deal with it sometimes. She says that (my mentor) will just drink too much sometimes when he is alone at the house, and will tell her the same stories over and over again when she gets home. She also said that she is taking time for herself (yoga class, time with friends, etc...) so that she doesn't get too overwhelmed. (606\_2011.11)

Another student attended a community meeting in which her mentor volunteered to get their coats before leaving and returned with several coats, but none that belonged to them. She had this empathic reflection:

(My mentor's wife) also seemed frustrated by the coat situation, like it was difficult for her to see him struggle with such a simple task. I know it must be difficult for her to go through this with him. (705\_2011.11.29)

A smaller percentage, only 3% (N=2) recognized how well the caregiver was coping with the illness. This student expressed admiration for the caregiver's handling of a distressful situation when the person with a younger onset dementia became very concerned that she had forgotten to cancel lunch with her mother and became insistent that her husband contact a number of people to make sure that the message was given to her. She also included a brief statement of 'alliance' with the caregiver in the following excerpt:

It was interesting to see how (my mentor's partner) handled (my mentor) being stressed out about forgetting to cancel lunch with her mom- he was very calm about it and reassuring but also called everyone that (my mentor) asked him to. I was very impressed by his ability to handle her distress (and slight overreaction) without seeming stressed himself. (610\_2011.2.24)

### **Matrix Coding**

The researcher's strategy for presenting findings in this chapter has been to discuss the coding process and present the resulting themes using continuous text in addition to reporting the frequency of codes quantitatively. In NVivo, matrix coding queries using contextual variables, including attributes, or variables, along with more detailed methods of cross case analysis, play a part in identifying patterns of association and difference. Matrix queries also make the checking of a series of associations more efficient (Bazeley, 2012). Matrix querying was used to compare themes with students' demographic and experiential variables. These include gender, previous experience with older adults, previous experience with persons with Alzheimer's, number of hours spent

in activity, number of submitted journals and the time point in the year (early, middle, late) in which the activity took place. In order to capture the relationship of the students' journal content to the time-point submitted, an experience stage was created by dividing the academic year into three sections: Early (October-December), Middle (January-March 15), and Late (March 16-May). The number of journal submissions by each student was also categorized into three sections: (1) 2-3 journals, (2) 4-5 journals and (3) 6-9 journals over the academic year.

A matrix query of all themes vs. attributes (see Appendix C) showed a number of attributes (variables) that were associated with themes in a particular way. The three highlighted in this study were gender, stage of experience, and level of previous experience with persons with dementia. Each of these is discussed below.

Table 12 shows journal entries coded as expressions of 'perceiving mentor's mood' by student gender. This theme was coded 88 times (62% of total references) in the female students' journal entries, and 55 times (or in 38% of the data) in the male students' entries. Feeling empathy toward the mentor was coded 11 times (79%) for females and 3 times (21%) for males. References coded to 'feelings of camaraderie-friendship' revealed that women wrote more about this 74% of the time compared to men (26%). While the sample included slightly fewer (44%) females compared to 56% males, when how many journals were submitted, a total of 492 by females (mean=4) and 187 by males (mean=1.4), was factored into the analysis the meaningfulness of the frequent references may be explained by the fact that the female students wrote more than the males. To explore if content about emotional responses differed between men and

women, the corresponding narrative data was reviewed; however, there were no significant differences in the type of expressions of feelings between the male and female students. These findings will be discussed further in the next chapter.

Table 12. Matrix Query Themes by Gender

<b>Themes</b>	<b>Total</b>	<b>Female</b>	<b>Male</b>
SEEING BUDDY AS MENTOR	47	20 (43%)	27 (57%)
FOCUS ON RELATIONSHIP	226		
Feeling increasing comfort over time	36	17 (47%)	19 (53%)
Feeling camaraderie-friendship	34	25 (74%)	9 (26%)
Feeling enjoyment-fun	73	46 (63%)	27 (37%)
Being aware of communication	44	29 (66%)	15 (34%)
Expressing discomfort	39	24 (62%)	15 (38%)
FOCUS ON THE PERSON	157		
Perceiving mentor's mood	143	88 (62%)	55 (38%)
Empathy	14	11 (79%)	3 (21%)
FOCUS ON ILLNESS	124		
Expressing clinical concern-opinion	28	15 (54%)	13 (46%)
Expressing curiosity about disease symptoms	25	20 (80%)	5 (20%)
Recognizing mentor's symptoms	71	44 (62%)	27 (38%)
AWARENESS OF SELF			
Experiencing a change in perspective/attitude	50	23 (46%)	27 (54%)
Expressing own emotional response to symptoms	15	7 (47%)	8 (53%)
FOCUS ON THE CAREGIVER	60	36 (60%)	24 (40%)

The results of a matrix query of themes by experience stage are reported in Table 13. The number of references coded during the early stage of the experience was significantly greater at 44% (N=298) than the last third of the year where 17% of the coding occurred. (N=114). A likely reason for this lower count is that, while the students submitted a mean of four journals per student over the course of the academic year, a total mean of 40 journals was submitted during the early experience stage, 45 during the middle stage and 22 during the last stage. As the year progressed, students

submitted fewer journals and spent fewer hours with their buddy compared to the beginning of the year, in spite of close program oversight and the requirement that students see their buddies at least four hours a month. There are many factors that could play a role into this decline, such as the weather in Chicago along with the cumulative effects of the program year, additional responsibilities and exams.

Table 13. Matrix Query Themes by Experience Stage

<b>Themes</b>	<b>Total</b>	<b>Early</b>	<b>Middle</b>	<b>Late</b>
SEEING BUDDY AS MENTOR	47	30	10	7
FOCUS ON RELATIONSHIP				
Feeling increasing comfort over time	36	19	11	6
Feeling camaraderie-friendship	34	18	10	6
Feeling enjoyment-fun	73	36	27	10
Being aware of communication	44	27	10	7
Expressing discomfort	39	16	21	2
FOCUS ON THE PERSON				
Perceiving mentor's mood	143	51	67	25
Empathy	14	10	4	0
FOCUS ON ILLNESS				
Expressing clinical concern-opinion	28	3	19	6
Expressing curiosity about disease symptoms	25	6	13	6
Recognizing mentor's symptoms	71	29	28	14
AWARENESS OF SELF				
Experiencing a change in perspective/attitude	50	24	16	10
Expressing own emotional response to symptoms	15	6	5	4
FOCUS ON THE CAREGIVER	60	23	26	11
Total References	679	298	267	114

Table 14 shows the results of a matrix query of themes by previous the past experience with persons with dementia. Those with previous experience had more expressions of camaraderie, feelings of comfort and made more self-reflective comments

on their experience. On the other hand, not having previous experience made a marked difference in the expressions regarding ‘change in perspective’, statements regarding their buddy as a ‘mentor’, ‘curiosity regarding the disease symptoms’ and their own ‘emotional response to symptoms’ marked by a ✓ in the table below.

Table 14. Matrix Query Themes by Previous Experience with Persons with Dementia

Themes	Total	Experience	No Experience
SEEING BUDDY AS MENTOR	47	18	29
FOCUS ON RELATIONSHIP		114	80
Feeling increasing comfort over time	36	20	16
Feeling camaraderie-friendship	34	24	12
Feeling enjoyment-fun	73	47	27
Being aware of communication	44	30	14
Expressing discomfort	39	19	20
FOCUS ON THE PERSON		79	79
Perceiving mentor’s mood	143	71	73
Empathy	14	8	6
FOCUS ON ILLNESS		48	73
Expressing clinical concern-opinion	28	10	18
✓Expressing curiosity about disease symptoms	25	3	22
Recognizing mentor’s symptoms	71	37	34
AWARENESS OF SELF		23	40
✓Experiencing a change in perspective/attitude	50	19	31
✓Expressing own emotional response to symptoms	15	4	11
FOCUS ON THE CAREGIVER	60	39	22
Total References	679	349	335

As Bazeley (2012) states, it’s not enough to just look at the numbers, the researcher needs to return to the narrative data for further analysis; therefore, it was



important to review the journal references for these four themes to look for qualitative differences between those with previous experience with persons with AD and those without. First, the emotional response to symptoms was reviewed. It's difficult to compare 11 references to only four; however, there appeared to be more intense emotional content in those without previous experience with persons with dementia. For example, one student stated

Sometimes it was hard for me, emotionally, to see (my mentor) struggle.  
(607\_2011.1.12)

and

(My mentor) tells me that she was diagnosed three years ago (when she was 57), that she had first really noticed it when she started to have trouble remembering personal details of patients in her social work clinic (she used to have an astounding memory for personal details, which I find incredibly sad).  
(702\_2011.10.18)

Another student expressed thoughts on mortality,

...on the other hand it made me think about her trajectory down the line and the tragedy of how it could get worse. From there, I couldn't help thinking about our mortality as people, and the unique tragedy of losing one's mind as they age because of disease. (704\_2011.10.29)

Compared to those with previous experience with AD such as

I also could not help feeling pity for her. (603\_2010.12.6)

and

I found this very sad, as it was the first time I'd seen (my mentor) exhibit the behaviors I've seen in my grandparents, who have more severe dementia...it made me sad to anticipate the changes that we might see over the whole year.  
(705\_2011.11.29)

It is important to consider what may be causing those with no experience to write with more intensity. Perhaps they have not had the opportunity to examine their feelings

about disability, cognitive impairment and loss of functioning. This experience is giving them the chance to examine their reactions and emotions. It is not surprising that they respond to their mentor with emotions of their own. The lack of knowledge and experience with persons with dementia may increase their feelings of grief, fear, and powerlessness in the face of their mentor's condition. For a profession whose aim is to cure and make people better, this is an illness for which none of these things can be accomplished.

Those with experience with AD referenced the theme 'change in perspective' 19 times compared to those without previous experience who referenced it 31 times. The content of the references in the theme 'experiencing a changing perspective/attitude' were not noticeably different. Both those with and without initial "prejudices" discussed how surprised and impressed they were at their mentor's ability to cope with their cognitive changes, their optimism, active lives, and methods of compensation. This resulted in the students forgetting about the 'disease while with their mentor and allowed them to get to know them as a person and not defined by their symptoms or illness.

Examining the references to 'expressing curiosity about disease symptoms', 19 of the 22 responses were made by only one student who did not have past experience with AD, three in November, four in January, seven in March and two in April. This student wrote extensively throughout the year, only one of two students (both of whom were female) who submitted a total of nine journals. This demonstrates one of the limitations of the study discussed below, that some students simply wrote more than others. Nevertheless, this particular student's (subject #504) reflections on her change of

perspective are worthy of documentation of the theme ‘expressing curiosity about disease symptoms’ from someone who had no previous experience with Alzheimer’s disease. In addition to the two previous excerpts on pages 118 and 119 provided by this student, additional references where she uses her journal writing to reflect on her curiosity regarding her mentor’s symptoms include:

Invariably she will ask multiple times during a meeting where I live, and today was no exception. Then at almost every lull in the conversation she would ask me what I liked to do for fun, followed up by ‘do you like movies?’ I think she asked me about 5 times over the course of the visit. Twice we got onto the topic of healthcare and expectations about how things will change in the future and how it has changed in the past, and both times (my mentor) wondered aloud how cavemen had taken care of themselves. I thought it was fascinating that both times her brain jumped to this thought. I guess it’s not surprising but I found it interesting...I think it’s interesting how much (my mentor’s) memory fluctuates in the course of a meeting...I guess I’m curious as to what pieces of information, if any really, get cemented in her mind. Does she do better with remembering faces/things versus information or details? (504\_2010.3.4)

And, in this reference, the student marvels over how her mentor repeatedly makes the same statements in exactly the same way with no memory for having done so a few minutes before. At one point in her reflection, she wonders if her repetition was purposeful as an attempt to explain the symptom, rather than think that someone could actually ‘forget’ that quickly.

I have noticed that (my mentor) has a few topics of conversation that she always goes back to. These include what I like to do for fun, do I like movies, are my parents doctors, how long is medical school. It is interesting because whenever she asks me these things she asks in the exact same manner. At least three times she has asked ‘Now your parents are in medicine, right?’ It is always worded the exact same way and while I always say no, she never retains the information. She remembered that she’s going to a gala event with her daughter and son in law but did not remember that I would be there as well. She never remembers the answers to the questions that she asks me repeatedly every visit and I wonder if these are ways to keep the conversation going and she’s not invested in the replies. This visit, unlike most, she knew that I lived downtown and instead of

asking many times (as she usually does), it didn't really come up. Also, I mentioned that it was Earth Day and she said she knew, she had seen it in the paper this morning. I wondered if she actually remembered seeing it or if she was covering because she thought it was a thing she should have known. Why would the fact that it was Earth Day occupy a spot in her memory when so many other things don't? (504\_2010.4.22)

This particular student wrote significantly more than her peers and expressed much curiosity about her mentor's symptoms and how the disease manifested itself. She explicitly wanted to know what brain mechanisms were causing the cognitive changes. She reflected intellectually regarding the clinical phenomenon that she was seeing and experiencing.

### **Conclusion**

The present study was a qualitative content thematic analysis of three years of journal data submitted by medical students in an experiential mentorship program with persons with dementia. Analyses yielded six major themes and 12 subthemes. These qualitative data were rich in capturing the impact of the Buddy Program on students' attitudes, perspectives, knowledge growth, and viewing the patient as person in a social, non medical context. Matrix coding queries demonstrated differences between the amount and thematic content of data written by women and men, with women writing significantly more, particularly in the areas of 'Focus on the Person' such as perceiving mentor's mood' and 'feeling empathy toward mentor', and a subtheme of the focus on the relationship, that is, 'feelings of camaraderie\_friendship'.

Previous experience with persons with dementia revealed differences in areas of expressions of camaraderie/friendship, feelings of comfort, and self-reflective comments on their experience. Those without experience with persons with AD had more

documentation on what they were learning from their mentors, more curiosity regarding the disease, more responses reflecting a changing perspective and more emotional responses to the symptoms they were observing in their mentor.

An in-depth discussion of these results is the subject of the next, and last, chapter.

## CHAPTER SIX

### DISCUSSION AND IMPLICATIONS

The aim of this study was to understand the experience of first year medical students who took part in an experiential learning and mentorship program with persons diagnosed with early stage dementia (the student's mentor) over the course of an academic year. Students and persons with dementia were brought together for the purposes of developing a friendship, not a clinical relationship. The students were in a position to learn from the person with dementia, not to study them. The person with dementia was 'positioned' in a meaningful role and the student had the opportunity to witness their experience living with a chronic illness such as Alzheimer's disease or other disease causing dementia.

Previous research has focused on pairing medical students with older adults to reduce stigma, demonstrating that student attitudes toward older persons are improved by these nonclinical geriatric experiences. However, few studies have focused on persons with dementia. During medical school training, interactions between students and persons with Alzheimer's disease and related disorders are often confined to clinical encounters. This study deliberately put the student and person with dementia in a neutral setting and the student was asked to submit reflections of their experience to the researcher after each activity. This study contains the results of a rigorous analysis of

students' reflections on their experience with persons with dementia over an academic year.

The methodology used for this study was qualitative content thematic analysis of first year medical student journals documenting their experience. The journals were analyzed to reveal information about the students' experience. A technique of coding and re-coding was applied over the course of four months and 18 time points (weekly) to develop themes that portray the students' experience. The impact of the experience was the goal of this investigation, based on the accounts of the people undergoing the experience (Polkinghorne, 2005). The data used to evaluate the impact were derived from an intensive exploration with the 'narratives' or the medical students' journals or narrative data. Overall, it was through the reading and analysis of these journals that captured the key elements of the program's impact on the student.

### **Results and Theoretical Framework**

Results were multi-dimensional. Students made observational statements regarding their mentors' memory loss and other symptoms and expressed subjective introspective reflections about the experience. Thematic results revealed six major themes: students': (1) view of the buddy (or person with dementia) as a mentor; (2) focus on the relationship; (3) focus on the person; (4) focus on the illness; (5) awareness of self; and (6) focus on the caregiver.

In this section, the identified themes are interpreted within the theoretical constructs described in Chapter Three: contact hypothesis/intergroup contact theory, person centered theory/personhood and social constructionism.

### **The Contact Hypothesis/Intergroup Contact Theory**

Allport's (1954) contact theory maintains that bringing groups into contact under favorable conditions is an effective way to reduce prejudice (Pettigrew & Tropp, 2008). These conditions include cooperative interactions with members working towards a common goal, supported by key authority figures, and the perception that participants possess equal status within the contact situation.

This study required first year medical students and persons with early stage cognitive impairment (mentors) to spend at least four hours a month over eight months together in activities of their choosing. The students' journal reflections of their time together revealed students' reactions, thoughts and feelings over the development of the relationship.

Allport's (1954) contact hypothesis was supported by key theme 'Awareness of Self' extracted from the data; and in particular, the subtheme of students' recognition of a 'changing perspective or attitude' from their preconceived notions about persons with cognitive impairment. Students expressed how surprised, amazed and impressed they were by their mentors' knowledge, ability to cope with symptoms, and sense of optimism. Their mentor did not meet their initial concepts or expectations of what it is like to live with dementia. The journals contained revelations of their initial prejudices and how they were modified through the experience of getting to know their mentor. Thus, Allport's theory that contact reduces prejudice was borne out by the study results.

For example, several students discussed their preconceived notions of what they expected from their mentor, such as,



I expected her to have a more difficult time maintaining long conversations. I was absolutely wrong (501\_2009.11.14)

and

I originally thought (my mentor) would not be as aware and in control of his thoughts and ideas, but I could not have been more mistaken (502\_2010.1.21)

and

I am surprised because I had almost forgotten already that she had Alzheimer's, and I was meeting her as part of the Buddy program. This person, really? (702\_2011.10.18)

The fact that the students with 'no experience with persons with Alzheimer's disease' had the greatest change in perspective, more curiosity regarding the disease symptoms and greater emotional intensity in their reflections further supports Allport's hypothesis. Students who lacked previous knowledge and experience with persons with dementia not only had the greater *potential* to be more intensely affected by the experience, but the results revealed this to be true. Such improved attitudes could ultimately contribute to students taking a more humanistic approach to the care of persons with dementia in their future work. Under the major theme, 'Focus on the Relationship', 28% of the students expressed 'increasing comfort level over time' with their mentor, further supporting the notion that with increased exposure, there is increased growth and adaptation over time. For example,

It's very hard for me to be one on one with people, especially those that are older than me, but I'm, finding it easier and easier to interact with (my mentor) which I really like. (701\_2011.10.8)

Of course, an important question is how or will this generalize to other experiences with older adults and persons with cognitive impairment over time and the long-term impact.

The results of this study demonstrated that the students' experience over the course of the year in the Buddy Program was effective at combating the perceived social stigma of dementia. This is a very important finding as stigma underlies many of the barriers for health care access among persons with dementia. Findings from the work of European researchers (Vernooij-Dassen et al., 2005) highlight how the perceived stigma associated with dementia among affected persons and their caregivers can lead to delayed diagnosis and treatment. Clark (2005) also asserted that negative stereotypes and ageism, which lead to the belief that cognitive decline is a normal part of aging, can lead to older adults with cognitive impairment being more reluctant to express their needs. One can conclude that this resulting awareness of self in relationship with others and the students' changing perception of living with dementia helped to humanize the experience and alter their preconceived notions.

### **Person-Centered Theory/Personhood**

Society has negative stereotypes for both age and cognitive impairment (Scholl & Sabat, 2008). The challenge for healthcare professionals is to combat the harmful effects of these stigmas and maintain a focus on personhood of the diagnosed individual. Fundamental to the philosophical and sociological position of personhood is the inherent value, intelligence, history and a present that all persons possess. Caring for persons with dementia requires the clinician to continue to seek, and not to dismiss, the 'person'.

A primary method by which personhood was supported in this study is through the buddy program's premise of 'positioning' the person with dementia as a mentor to a young first year medical student. Therefore, the student had the opportunity to look beyond the label of 'dementia patient' that they may see in the clinical setting. The student is told that the person living with cognitive changes has something of value to impart to them. It is this focus on the remaining strengths and abilities, and not the focus on their 'deficits', that allows the mentors' sense of self and personhood to be maintained.

Content analysis of medical students' journals and resulting themes and sub-themes supported the students' beliefs regarding the personhood of their mentor. More specifically, they recognized the uniqueness, remaining strengths, positive functions and characteristics of each person and the ability to live in relationships and experience interdependence and interconnectedness (Harrison, 1993).

Students expressed sensitivity to the fragility of the self in persons with dementia through their reflections on how they were communicating with their mentor. There were numerous examples of students' reflections on their attempts to not openly express their frustration at their mentor's repetition, recognizing that they needed to allow more time for their mentor to respond and thus, reflecting on learning to be patient. Students also reflected on feeling helpless, not knowing what to say in the face of their mentors' sadness, grief and frustration at their symptoms. However, this response to recognizing the person behind, or in addition to, the disease symptoms allowed compassion for the person to develop.

Students were able to acknowledge the adaptive capabilities of their mentors in face of the perceived consequences of the dementia. They saw their mentors striving to maintain their independence in their interactions with their caregiver in an effort to maintain their personal identity.

The major theme of the ‘focus on the person’ involved two subthemes; ‘perceiving mentor’s mood’ and ‘feeling empathy toward mentor’. Of all the subthemes, ‘perceiving mentor’s mood’ was coded the most frequently. These entries revealed the students’ sensitivity to various emotional states and ability to hear first-hand how a person is coping with illness. Mood states ranged from happy and upbeat to sad and discouraged. The lengthier entries were those that described the struggles their mentor experienced and are linked to how the student understood their mentors, such as the student who expressed concern regarding what she perceived as her mentor’s loneliness, lack of purpose and lack of social engagement.

She described it as feeling like she was ‘just here’. I took that to mean she had no real purpose; she had nothing to accomplish in a day and very few people to see. (504\_2010.2.18)

### **Social Constructionism**

Each of the themes are linked in some way to interactions between people. Snyder (2006), a social worker whose work has focused on the subjective experience of dementia writes, “One’s identity or personhood is developed, sustained and transformed in and through communicative relationships, both immediate and within society at large” (p. 268). Charmaz (1991) describes how the worlds of some people shrink when immersed in the daily aspects of their illness and they can become cut off from their family, friends

and others in their community. She describes how the foundation for a sense of self can be lost when not with supportive others.

The students' reflections demonstrated recognition of how their communication style positioned the person with dementia. For example, students discussed their preconceived notions of persons living with cognitive impairment and how these notions expressed themselves in their interactions. Some students expressed awareness of their stereotyped expectations and their potential for condescension and distancing in the language they used. For example,

I've never talked about the science of AD to a person with AD before and it really made me question if the way I speak about the disease is too impersonal and cold. (705\_2012.1.8)

The buddy program has the potential to transform the kinds of conversations these future physicians have with their patients. This experience created a venue for creative and open conversation to occur within the borderland between 'patient' and 'physician'. The students revealed their sensitivity to talk that is respectful and some had conversations that exuded a sense of energy and sent their thoughts in new directions. For example,

Our dinner conversation was incredibly varied, .....convoluted and deep .... which happens to be the kind that I most enjoy. ...it felt to me like (my mentor) was simply another good friend of mine. (704\_2012.2.25)

Dean (2007) discussed that at the heart of the concept of dialogue are conversations in which participants "strive to address one another as equal subjects with equal power and opportunity in the conversation" (p. 48). Furthermore, dialogue can lead to transformation if people are truly open in conversation and gain deeper understandings

of one another over time. Connections are achieved by reflecting on what is said. Self-understanding is enhanced as participants come to see themselves through the eyes of another. Dean references the work of Rozas (2004) who wrote that as participants become connected to each other's experiences they begin to define and redefine themselves within the interaction. It is in this sense that the self exists and is transformed through dialogue with others. It is not just about the content of conversation, it is about listening and reflecting as well as speaking.

The type of dialogue to which Dean (2007) and Rozas (2004) are referring was reflected in students' comments on their communication with their mentors. They repeatedly indicated their belief and increasing understanding that the disease did not define the person with dementia. This was a central theme and one many said they hoped to remember when they are in clinical encounters with patients farther along in their training.

An early understanding of good patient-physician communication has the potential to impact the way medical students and doctors interact with patients and families (Makoul, 2003). This may be challenging though, as Mintz (1992) considers how language is deeply ingrained in medicine as historically devaluing and distancing to patients and may serve a legitimate offer of emotional protection.

While using non-distancing discourse all of the time may be very difficult, using more humanizing language has the potential to improve relationships with patients and families. It may also facilitate the development of a non-authoritarian medical relationship in which the doctor is working with the patient rather than merely working

against the disease. In medicine, the patient is often described as a 'case'. Humanizing the encounter may change the physician to talk about the person with an illness. Perhaps these future physicians will also speculate on the non-medical factors influencing the illness or treatment, and to recognize, in general, the personal contribution on both sides of the physician-patient relationship. In practice, the students' experience in this study may result in a recognition of the holistic approach to the care of patients with cognitive impairment and their families and the recognition of the value and necessity of a multidisciplinary team to integrate the biology, psychology, social and ethical concerns and the cultural and spiritual aspects of their patients.

Whether it is called the biopsychosocial perspective or medical humanism, the recognition that medical practice is interactive and that the biological interacts with both the psychological and the social is a key outcome of this study. It is seeing the 'patient as a person' embedded in their historical relationships and traditions or as Hughes et al. (2006) called 'whole sight'. How can this sense of 'whole sight' influence how medical practice is conducted? The themes expressed by these students; that is, recognizing and valuing the person with the illness as a mentor; focusing on their student/mentor relationship; recognizing the caregiver's experience, and being aware of themselves in a relationship in addition to increasing their knowledge about dementia, contributes to a holistic understanding of the person which has the potential to influence their future practice of medicine. The following discussion moves beyond the theoretical framework to further reflect on the resulting analysis.

### **Narrative Competence: Developing Capacity for Empathy and Reflection**

In a national evaluation of ten senior mentor programs, Eleazar et al. (2009) found that many program faculty thought the student-mentor experience might also be influencing the formation of something deeper; perhaps student empathy, patient-centeredness, or the ability to “individualize” people, particularly reflected in publications by Stewart et al. (2007) at the University of South Carolina medical school and Hoffman et al. (2006) at the University of Missouri (Columbia) Medical School on their individual senior mentoring programs.

The process of engaging in an authentic relationship with a person with cognitive impairment and writing and reflecting on the experience may influence what Charon (2001) describes as “narrative competence...that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others” (p. 1897). With narrative competence, “physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care” (p. 1897). Practicing medicine is an intersubjective experience, requiring the engagement of one person with another. Authentic engagement has the potential to be transformative for all participants.

The buddy program is an opportunity for first year medical students to engage in an authentic relationship with someone with dementia and the opportunity to reflect on the experience outside of the clinical setting, This is an experience they will hopefully take with them into the clinical setting – the recognition of the personhood of the



individual patient and the significance of their relationship on their patients' health and welfare. Perhaps this experience will result in students' ability to be more open in their communication and therefore, more engaged in authentic and effective care.

### **Self-Awareness of Personal Emotions**

The buddy program encouraged students to reflect on their thoughts and feelings about their mentor and while many expressions were cheerful and positive, some students took the opportunity to talk about their sadness at the symptoms they were observing in their mentor and the inevitable decline they faced. Some students expressed fears about the decline they may see over the course of the year and others commented on their grief over their mentor's changes. These students recognized that dementia is a neurodegenerative progressive illness for which there are few medical treatments and no cure. This experience is different from that in medical disciplines where there are treatments and cures and it delivers the message that they will encounter patients for whom there is little hope of recovery.

While the program did not explicitly counsel students on their emotional responses to their mentors, their reflections on their emotional reactions in their journals provided an opportunity for them to examine this universal response to patient care. Not examining these feelings of helplessness may lead to disengagement from working with persons with dementia or have negative practice effects for those who do, making them either over- or under-engaged in their care. Acceptance and awareness of this phenomenon are prerequisite to the self-knowledge required as a clinician (Gorlin & Zucker, 1983). Although social workers and psychiatrists have long recognized the

importance of transference (patients' feelings about clinicians) and countertransference (clinician's feelings about patients) and have used recognition and naming of these emotions as a therapeutic modality, most nonpsychiatrists are not trained to pay attention to their emotions (Meier, Back & Morrison, 2001) and as a result do not have the opportunity to examine the reasons for them.

### **Patients Mentoring Students**

Patients have been used in medical education for many years with, traditionally, a relatively passive role, serving as a live specimen upon which to practice examinations. However, increasingly with changes in curriculum, patients are seen as having a contribution to make to medical students' education and training. One qualitative study examined patients' active role as teachers from the patients' point of view (Stacy & Spencer, 1999). Patients saw themselves as experts in their condition and as facilitators of students' attitudes and professional skills.

Similarly, the person with dementia in this study was purposefully called a mentor in their relationship with the first year medical student and as such, a facilitator of the students' attitudes and learning. Typically people with dementia are referred to in the literature as victims, sufferers, and care recipients, all terms that imply that people with dementia are empty passive vessels, not people with the possibility or capability of mentorship qualities. Rarely in the research arena is the person with dementia considered a mentor, a person capable of providing advice and guidance. However, in this study persons with dementia were cast as collaborators or partners in education and research.

It was an interesting finding that the majority (70%) of the students did not refer directly to what they were “learning” from their mentor in their journals. However, the findings illustrate the indirect mentoring that the person with dementia provided in the students’ reflections.

### **Focus on the Caregiver: The Importance of the Caregiver’s Perspective**

Family caregivers play a vital role in the care of the person with dementia and need a great deal of support, assistance, and understanding from the formal care system, including their physicians. There is often conflict among different family members about caregiving and the stress of caregiving coupled with complicated relationship histories can erode the ability of the family members to support one another.

Students described their observations of primarily supportive roles that the caregivers play in the lives of their mentor; however, some students witnessed distress and conflict firsthand between their mentor and their caregiver and, as a result, some students were able to describe empathic responses for the stress the disease can cause in these relationships. Understanding the importance of this relationship in the care of persons with dementia is crucial to their future clinical work and reflects the biopsychosocial framework; that is, seeing the person with dementia and their caregiving family from a holistic and systemic perspective and recognizing the complexity of relationships among them.

All relationships have preexisting dynamics, strengths and vulnerabilities. The challenge of dementia likely affects both the patient and family’s adjustment and ability to cope. Graham and Bassett’s (2006) longitudinal ethnographic study of persons with

Alzheimer's disease and their family caregivers present evidence that caring relationships are "dynamic co-constructions built upon everyday events, interactions, environments, and disease progression" (p. 335). Many of the students were able to see this first hand and it is an important finding that the students reflected these observations in their journal entries.

Another area that students observed and reflected upon in their journals was the challenge of simultaneously being respectful of the autonomy and independence of the person with dementia while also being helpful and caring. This is a tension that family members face in their daily encounters and in their ongoing planning for the future. Similarly, the students reflected upon their own uncertainty about what to do when encountering their mentor exhibiting, for example, difficulty finding words, forgetting that they had eaten, or obviously struggling with handling money. The students were faced with choices on how much to intervene, to help, and to counsel their mentors on decisions with which they were not in agreement while also being respectful.

#### **Clinical Concern/Opinion: Students' Reflections on the Person in Environment**

Recognizing autonomy of the individual is related to the expressions students made regarding their mentors' clinical symptoms. In addition to students' observations of their mentors' relationship to others, students expressed concern over their mentors' living situation, for example, whether they were safe in their homes or whether they should be driving. They also expressed concern regarding what they viewed as a lack of a support network and their mentors' increased isolation, in addition to the lack of meaningful activity. They essentially saw the person with dementia as part of a larger

world that the mentor and caregiver were trying to navigate. This has implications for their role as a future physician. The students saw how vulnerable living with dementia is for their mentor. Students' recognized, named and focused on symptoms in their reflections. For example, they described examples of memory loss and at times gave opinions on what their mentor should do about them. Their role as a future doctor was never far from their thinking in their interactions with their mentor.

However, they also recognized the personal experience of illness and demonstrated an ability to develop a connection with their mentor that was not a clinical relationship and, for most, one of friendship. This connection validated the person with dementia, gave purpose and meaning to the person, and repositioned the person with dementia as a person of worth (Sabat, 2001).

### **Gender Differences**

Students were required to write a journal reflection following each activity with their mentor in order to provide a vehicle for personalizing the experience and make sense of it both intellectually and emotionally. It emerged that the female students wrote more than twice as much as the male students. This prompted a search of the literature on gender and journal writing, which turned up surprisingly very little. One professor of English explained, "Journals have a long history as education adjuncts, and school journals have become increasingly popular across the curriculum as a tool for learning at all educational levels since the 1960s" (Gannett, 1994, p. 280). Journals have a "gendered legacy" (Gannett, 1992, p. 54), as women have been more frequently the keeper of journals and diaries than men, beginning at a very young age.

Gannett (1992) found in the classes she taught in which journals were required, that men tended to state more facts and were not very interested in self-disclosure or self-examination on paper. They were more 'distant' in their writing, focusing more on the external events than introspection. On the other hand, women were much more self-disclosing and had what she called "thick descriptions" of personal and interpersonal events or relations that went on for several pages. She found that the average woman's journal was over twice as long as the average man's. Even more telling was that over half of the women were actually keeping their own personal journals in addition to the journals they produced for class. None of the men who completed the class reported having kept journals previously, except those who had been "forced" to do so in previous classes.

Belenky, Clinch, Goldberger, and Tarule (1986) in *Women's Ways of Knowing* discussed that coming to 'voice' is a central metaphor for intellectual development. Gannett (1992) contends that women use journals to find the voice that is silenced or discouraged in educational settings. Although these references are dated, the findings in the present study support that journal writing continues to have a gendered bias and it would be worth further exploration to review the literature on the role of women in medical school for any clues as to whether or not writing is a surrogate for expressing oneself that is stymied in other arenas.

Additionally, although the women did write more than men, the two themes that were coded for women more frequently than men were empathy (79%) and camaraderie (74%) or feeling of friendship, reciprocity, and mutuality. These results support previous

research on gender differences in empathy scores, with female students scoring higher on the Jefferson Scale of Physician Empathy (Chen, Lew, Hershman, & Orlander, 2007; Hojat, Gonnella, Mangione, Nasca, & Magee, 2001; Tavakol, Dennick, & Tavakol, 2011). Brazeau, Schroeder, Rovi, and Boyd (2011) found that medical students who participated in any service activity during medical school had higher empathy scores at graduation than students who did not participate; however, in that sample, more women than men reported participating in service activities (92.8% versus 77.6%).

Pitkala and Mantyranta (2003) also found gender differences in a qualitative content analysis they conducted of third and fourth year medical student diaries during their first clinical year. They report differences between the genders in how they report various feelings in their writings. Female students more frequently reported inferiority; however, also expressed more feelings of closeness to the patients; however, some male students also expressed their feelings openly and deeply, leaving it difficult to interpret. They, too, found that some students were “scant and avoidant writers” (p. 176) focusing on objective events rather than exploring their own feelings in their learning diaries.

### **Focus on Illness – Dementia Education**

Students’ recognized, named and focused on symptoms in their reflections. For example, they made several references regarding their observations of symptoms they saw in their mentor and as shown, their observations reflected the heterogeneity of symptoms in dementia and of different illnesses that cause dementia. The buddy program provided the opportunity to educate medical students regarding the complexity of dementing disorders and the variability in their presentation; that is, forgetfulness,

visuospatial difficulties and language decline. The monthly process meetings allowed for students to hear from multidisciplinary clinical faculty: neurologists, neuropsychologists and social workers, regarding the broad spectrum of dementia symptoms, the diagnostic evaluation, including neurological examination, neuropsychological tests, and the psychosocial assessment and interventions provided by social workers. Students had the opportunity to understand that there is no “one size fits all” approach to dementia diagnosis and care of the individual and family. This multidisciplinary approach to the care and treatment of persons with dementia coincides with the emphasis on the biopsychosocial model of medical education. This holistic and interdisciplinary approach to the learning needs of health care professionals is necessary to meet the needs of the increasing population of older adults with dementia.

### **Implications for Social Work**

The impact of dementia on our society is expected to be catastrophic unless research finds better methods of treatment and prevention and the toll will be highest on the families who provide the majority of care. Social workers, whose focus and skills relate to the individual and environment and the interactions between them are some of the most appropriate professionals to serve the growing population of persons with dementia and their caregivers. But in order to do so, social workers must be knowledgeable about the illness, its course and its myriad effects on the individual, family and society.

Unfortunately dementia education is noticeably absent in graduate schools of social work, where gerontology courses tend to be very limited and those that do exist



spend perhaps one or two sessions focusing on dementia. Only one social work text has been written for social workers, *Dementia and Social Work Practice* (Cox, 2007). The implementation of the Buddy Program in schools of social work has the potential for increasing knowledge and awareness of dementia, its impact on the individual and family and expanding the crucial role of social workers at all levels of practice, policy and research.

In doing so, the key values of social work theory and practice will be promoted. Social work theory requires that the individual is seen within a larger context (person in environment), whether it is an 85-year-old woman with Alzheimer's disease living alone with no family, an adult daughter attempting to care for her mother 500 miles a way, or an 11-year-old child facing the changes in a parent with younger-onset dementia. All of these individuals live within larger family systems and when interfacing with a clinician, no matter the discipline, attention to this systemic context allows for a more holistic understanding and treatment that are grounded in this knowledge.

The measure of success for educating social workers and other health care providers about Alzheimer's disease and related illnesses may not need to develop practitioners whose focus is solely in this area, but rather to educate and broaden health care and social service providers about the intergenerational aspects of care and the importance of integrating aging and dementia in all practice areas.

### **Limitations and Researcher Bias**

Several methodological factors limited the study findings. First, participants were self-selected and this introduces a bias into the sample that likely influenced the results.

For example, students who volunteer for such activities are likely to be more altruistic and sociable than those who don't, more willing to expose their thoughts and feelings. Enrollment was limited to 10-15 students per year; approximately 10% of the medical school cohort; consequently the results are not generalizable. However qualitative research makes no claim to be representative of the population as a whole or even the specific group it is examining. The purpose of this methodology was to present a more in-depth, diverse, and complex picture of a phenomenon than had been previously reported in more objective terms. While the data for this study are narrative reflections of students' experience, they were produced in a situation where students were aware that the researcher would be reading them. Thus, conscious and unconscious presumptions and the desire to please may have guided their choices of what to write.

Despite the researcher's best efforts to recruit students who ultimately fulfilled the program requirements, there were complicating factors that arose over the course of an academic year that interfered with full completion of program requirements. Medical school is increasingly demanding as the year progresses and some students take on more extracurricular activities than they can handle. Others struggle academically and others have personal, family or health issues that arise. As a result, some of the students submitted more journals than others; therefore, those with more journal submissions have more coded references and their individual experience is more heavily weighted.

Additionally, narratives declined in number during the last third of the experience; thus affecting and limiting more comprehensive analysis of the experience during this time. This occurrence raises the following questions: (1) Did school become too intense

and the student too busy to see their mentor as frequently?, (2) Were declining journal entries representative of a waning interest in the program or getting together with their mentor?, (3) Did students have difficulty sustaining the relationship due to internal feelings of discomfort they were experiencing and not expressing?, (4) Did the progression of the disease and the mentors' visible worsening over time alter the student/mentor relationship? In spite of these limitations, the present study resulted in an understanding of the issues and complexities students faced in their experience. While the students may have decreased their journal submissions and visits over time, the quality of the data did not decrease with less quantity.

Yet another limitation is researcher bias. The study PI has a several year history of experience and work with first year medical students and persons with dementia in this program. Reflecting on bias or the process of self-reflection from a methodological sense is identified as reflexivity (Schwandt, 2001). The acknowledgement of biases, values and interests, or introspection is typical of qualitative research (Creswell, 2003). Rossman and Rallis (2003) describe the importance of reflexivity at several stages in the research. Identifying existing bias, as above, is important in setting the tone for the research. The phenomenon of looking at oneself and making sense of how someone else makes sense of the world is central to understanding the practice of qualitative research (Rossman & Rallis, 2003).

In preparation for data analysis, the PI was aware of how her own reactions to the students and the persons with dementia about whom they were writing influenced the results. Several of the mentors the PI knew well as a clinical social worker in the

Neurobehavior and Memory Clinic. Care was taken to make this study as unbiased as possible; however, selectivity cannot be eliminated in the researcher's coding of the data. The data do not speak for themselves; they are interpreted through the researcher's individual thinking and analysis. This is a qualitative study and the researcher needed to create a coding structure in stages and impose it on the data (LeCompte, 2000). Thus, the work also represents the researcher's own interpretation with respect to existing social work hypotheses and theories.

### **Implications for Future Research**

The results of this study add evidence that the Buddy Program meets the program goals; that is (1) increasing students' knowledge base about Alzheimer's disease and related conditions, (2) heightening students' awareness of skills and strengths that remain in people with Alzheimer's, especially in earlier stages of illness, (3) providing opportunities to witness firsthand how someone with early stage Alzheimer's responds to his or her own changing abilities, (4) familiarizing students with issues of the daily care and support of persons with Alzheimer's and their families and the most effective ways of communicating with persons with dementia, and (5) providing persons living with dementia an opportunity to serve as a mentor to a future doctor, regardless of their own area of expertise.

To date, the researcher has followed 110 of the 150 medical students in terms of residency choice. Although a discussion of the information derived from this far exceeds the scope of the present study, it is of interest that 73 percent have chosen patient-oriented fields such as internal medicine, family practice, neurology, geriatrics,

psychiatry, obstetrics/ gynecology and pediatrics. All of these future doctors, regardless of specialty are likely to come into contact with older adults and persons with dementia and/or their caregiving family members. Surveying these practicing doctors regarding the impact of the Buddy Program experience on their post-training practice would provide an understanding on the longitudinal effects of this experiential program.

Another direction future research might take is to add quantitative measures of empathy, stigma, and knowledge and attitudes and to collect these pre- and post-participation in the program. In addition requiring a pre program set of reflections including what they might anticipate once starting the program would offer a more direct link between pre-and post- experience effects.

Yet another area for investigation is the examination of the experience of the mentor and his/her family. Post program evaluations, focus groups and telephone interviews of persons with dementia and their caregivers make up evaluation data collected to date, but not yet analyzed.

### **Replicating the Study in Other Disciplines: A Case for Social Work**

Since Allport's (1954) theory of intergroup contact was supported by this study, it appears that students of disciplines other than medicine, such as social work, psychology, occupational and physical therapy and other allied health professions would experience similar results, providing an experiential non-clinical relationship to reduce stigma and increase comfort interacting with persons with dementia and an aging population.

How might the program be different for social work students? Due to the preponderance of women in the social work profession, it is conceivable that social work

interns may provide more in-depth reflections of the time they spend with their mentor. Due to the nature of social work education and the emphasis on human behavior in the social environment, social work students may spend less time expressing curiosity regarding their mentor's particular disease symptoms and brain function and more time on the relational aspects of living with dementia, particularly the family dynamics and the phenomenological or subjective experience of both the person with the illness and their families. One could expect that a focus on quality of life and non-pharmacological interventions would be present. Medical students had difficulty completely distancing themselves from their future physician role when with their mentor and social work students may find that they, too, are conducting an ongoing analysis of their mentors' psychosocial situation and what may be helpful to them.

Empowerment is a social work value. Due to the devastating images society continues to hold of persons with dementia; that is, of persons in the advanced stage of the illness, completely dependent on others for care, an experiential program for social workers and other disciplines would offer an opportunity to modify those images and recognize the remaining strengths and abilities in persons with dementia and the ways in which they can be empowered to continue to contribute to their families and society.

### **Summary**

The Buddy Program was developed for first year medical students and those in the early stages of cognitive decline. Persons with early stage dementia were experiencing a shifting in their role as a cognitively intact person of value in society to an increasingly devalued cognitively impaired person with little meaningful activity. The

program provided persons with early stage dementia an opportunity to contribute in a meaningful way to medical education.

Reciprocally, the Buddy Program offered first year medical students an opportunity to spend a significant amount of contact time with a community-dwelling person with dementia in a way that is not a detached clinical encounter. The experience allowed the students to establish an intergenerational relationship and friendship and observe firsthand the ‘biological’ changes, i.e., their mentors’ symptoms and how their mentors integrated those changes in psychologically and socially and the challenges that they faced.

The buddy program sought to influence physicians’ understanding of persons with dementia within the biopsychosocial context providing a more holistic view of the patient and family outside of the clinical setting, to provide opportunities for the patient and family to have a voice and for that voice to be supported, and to recognize all members of the multi/interdisciplinary team as integral to quality patient care. Based on their journal entries, students’ experience of the program revealed an influential early experience as they progress through their training. The researcher’s ultimate goal was to provide an experience that challenged students’ preconceptions of dementia and what it’s like to live with it. Results indicate that this goal has been met. The researcher’s hope in conducting this multi-year effort is to influence medical students to become more compassionate and skillful in their work with all vulnerable patients.

APPENDIX A

BUDDY PROGRAM OBJECTIVES AND CORE ELEMENTS



## **The Buddy Program Objectives and Core Elements**

- Provide an opportunity for individuals with Alzheimer’s disease (AD) or related cognitive impairment to mentor a first year medical student and influence their future clinical practice.
- Educate medical students regarding Alzheimer’s disease and related disorders and related cognitive impairment
- Improve students’ communication skills and patterns when interacting with older adults and persons with cognitive impairment
- Increase students’ awareness of skills and strengths that remain in people with cognitive impairment
- Provide the opportunity for students to see how someone with AD responds to his or her own changing abilities
- Familiarize students with care and support-related issues encountered by patients with cognitive impairment and their families.
- Introduce students to research and practice opportunities in neurology, geriatrics, and related fields.

### **I. Time Commitment Student Requirements**

Three hours of orientation on AD and related cognitive impairment and communication skills.

Five hours per month to the Buddy Program. Four hours are devoted to buddy activities, while the other hour is dedicated to monthly program lectures from the Neurobehavior and Alzheimer's Disease Center clinicians, and support/guidance from the Buddy Program faculty.

Written reports of activities immediately following the event to program faculty/staff.

A ‘reflection’ paper at the end of the year in addition to a program evaluation.

### **Mentor Requirements**

Four hours per month participating in an activity with the student.

End of the year evaluation of the experience via oral interview or written survey.

Monthly check-ins by program staff for feedback.

The Buddy Program runs on annual intervals. Each participant is asked to commit the entire academic year (September – May) to the program.

## **II. Application and Selection Process**

Students must submit an application to be considered for the program. Admittance into the Buddy Program is a selective process and students are interviewed by program faculty and staff to determine whether the student is able to make the necessary time commitment to the program.

Diagnosed persons are referred from the Memory Disorders Research Core or the Neurobehavior and Memory Clinic and are contacted by program staff/faculty to determine eligibility and interest in the Buddy Program. Interviews are held with individuals not known to program faculty/staff. All individuals must be diagnosed with Alzheimer's disease or related cognitive impairment.

## **II. Institutional Review Board (IRB)**

The Buddy Program is approved by the Northwestern University Institutional Review Board-Office for the Protection of Research Subjects. Both student and diagnosed individual must sign a consent form prior to their involvement in the Buddy Program. Program faculty is conducting research on program outcomes for both the student and mentor.

## **III. Activities**

Meetings and appropriate activities will be determined by the mentor, the family, the student, and professional staff and faculty. Appropriate activities might include: going to the movies, museums, enjoying hobbies together, exercising, shopping, or just engaging in simple conversation.

## **IV. Activity Journal**

Students are required to complete a brief journal entry at the end of each activity session. Journal forms will be provided to students. Completed activity journal forms should be e-mailed to Kristine Zachrich at k-zachrich@northwestern.edu.

## **V. Monthly Check-In**

Program staff will contact mentors and families on a monthly basis for feedback on their experience with the program.

**VI. Transportation**

Transportation to/from buddy visits is the responsibility of the student. Students should not be the passenger when the buddy or the buddy's caregiver is driving, nor should the student be in the position of transporting the person with Alzheimer's or their family member.

**VII. Activity Expenses**

Expenses for activities will be the responsibility of the student at the time of the event. However, the CNADC will reimburse students on a monthly basis for any expenses they may have accrued. The CNADC is unable to reimburse tax. The CNADC will reimburse up to \$150 for the entire year.

Students are required to complete a Traveler's Expense form and submit receipts at the monthly program meetings.

**VII. Orientation**

There will be an obligatory orientation for students. This consists of two 1.5-hour sessions conducted by the CNADC faculty. This orientation will cover the etiology, progression and treatment of dementia, as well as practical information on communication, caregiving, and the subjective experience of dementia via readings and video.

**VIII. Matching**

Matching is based on compatibility of interests, logistical concerns, and demographic preferences. The Program faculty meet with each student individually to facilitate the best match possible. The student and individual with Alzheimer's or related cognitive impairment meet at the Match Day Party,

**IX. Photographs**

Photographs will be taken of Buddy pairs at the Match Party. These photographs may be used for teaching, publications or presentations at clinical meetings. No other personal information will be included in the presentation.

**X. Clinical Opportunities**

If agreed upon by the diagnosed person and family, students will have the opportunity to accompany them to their scheduled Neurobehavior and Memory Clinic appointment with their doctor. These visits provide an opportunity to observe neurological, neuropsychological, and/or psychiatric assessments.

Students have the opportunity to shadow a clinician at other times throughout the year on a pre-arranged basis.

**XI. Professional Guidance**

The program faculty and staff will offer guidance throughout the program and are available to answer any questions/concerns that might occur while engaging in activities.

**XII. Certificate of Commendation**

At the end of successfully completing the Buddy Program year (5 hours to the program per month coupled with the appropriate evaluation forms), each student and mentor is given a Certificate of Completion from M.–Marsel Mesulam, M.D, Director of the CNADC and Program Director, Darby Morhardt, MSW, LCSW.

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APPENDIX B  
BUDDY PROGRAM MANUAL

# **The Buddy Program**

## **Pairing First Year Medical Students with Persons with Alzheimer's and Related Cognitive Impairment**

A program of the  
Northwestern University Feinberg School of Medicine  
Cognitive Neurology and Alzheimer's Disease Center

*The Buddy Program is supported by a grant from  
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from the National Institute on Aging to Northwestern University Feinberg School of Medicine*

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*The Cognitive Neurology and Alzheimer's Disease Center is one of 30 Alzheimer's Disease Centers in the United States designated by the National Institute on Aging. Founded in 1996, the CNADC is a multidisciplinary organization, dedicated to conducting research on brain mechanisms in mental functions, transferring the benefits of this research to patients with dementia and their families, and training researchers and clinicians to work in this field.*

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## INTRODUCTION

### **Purpose:**

The Buddy Program is a research based program pairing first year medical students with persons with mild Alzheimer's disease (AD) or related cognitive impairment over the course of an academic year. The Buddy Program has three aims: to provide a mentorship opportunity and social engagement for persons with AD, to offer an opportunity for both the person and family to share their experiences with the illness, and to give medical students the opportunity to get to know someone with dementia outside of the clinical setting. The Buddy Program aims to provide a mutually enriching experience.

### **History:**

The idea for a program to introduce medical students to individuals with dementia, to facilitate a more meaningful interaction, originated in the Neurobehavior and Memory Clinic of the Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC). The diagnosed person, a retired Northwestern physician with AD, and his wife expressed frustration that he was no longer using his experience and knowledge in any meaningful way. Although forced to abandon his life's work as a result of his cognitive decline, he was still able to impart valuable medical information and provide supportive direction and mentor, for a time, an interested medical student. The Buddy Program was developed and piloted in 1997 to provide first-year medical students the experience of getting to know a person with early stage of AD or related cognitive impairment and the opportunity to learn from them.

In addition to conducting research on treatment, cures and prevention, the CNADC has always placed a strong emphasis on helping to improve quality of life for diagnosed individuals and their families. Over the years, the CNADC has developed and enhanced early stage programming to help families cope with the diagnosis, combat the common stigmas of Alzheimer's disease, and investigate the potential benefits of non-pharmacological interventions. The Buddy Program was developed on the premise, that despite the diagnosis, persons can still maintain a meaningful quality of life and offers others a learning experience on their own terms. This program also combats the stigma that people with a diagnosis are defined by their disease. In spite of the cognitive and physical changes, they are still unique individuals with stories, experiences and ideas to share.

### **Buddy Program Goals:**

1. Educate students about Alzheimer's disease (AD) and related cognitive impairment.
2. Heighten awareness of the skills and strengths that remain in people with this disease.
3. Provide the opportunity to see first-hand how someone with AD responds to his/her own changing abilities.
4. Familiarize students with care and support-related issues encountered by persons with AD and their families.

5. Become familiar with the most effective ways of communicating with persons with dementia.
6. Introduce students to research and other career opportunities in behavioral neurology, neuropsychiatry, geriatrics, and related fields.
7. Provide individuals with AD an opportunity to mentor a medical student and influence their future clinical practice.
8. Provide individuals with AD an opportunity for preserved self-awareness, self-esteem and mood enhancement.

*“As I begin my studies in medicine, I worry if I will be a good physician. I ask myself, ‘Will I be able to help everyone? Will my patients learn from me? How can I communicate with them?’ I believe the Buddy Program has given me a valuable experience. I have learned how to conduct dialogue with patients and their families, taking into account the feelings behind the symptoms, and learn to put aside my own objective assumptions. A good doctor cures people’s symptoms. A great doctor is able to help a patient understand as well as look forward to taking steps to improve one’s health in both body and mind. Sometimes, all it requires is a friendly ear and a hot cup of coffee. I am very satisfied with my decision to join the Buddy Program. I would do it all over again.”*

– Student Buddy 2010

The Buddy Program is designed for persons with mild stages of dementia who live at home and are interested in mentoring a first year medical student.

### 1. Recruitment Methods

- An **“e-mail blast”** is sent to the entire first year class describing the program. **The Buddy Program information Flyer** is provided in this message, which outlines program goals and requirements.
- **Display at Fall Activities Fair** during Orientation Week showcases program goals, requirements and pictures of previous buddy pairs. Program staff are available to answer questions from students who visit the exhibit. Student buddies from previous years attend the fair to answer questions and assist in recruiting new students to the program.
- **Introductory Meeting** occurs shortly after the Activities Fair, an introductory meeting to the Buddy Program with program staff and previous buddy pairs is held. Here, a more in-depth discussion about the program occurs.
- **Student Application** is required for consideration into the Buddy Program.
- **Student Interviews** are scheduled following review of applications. This interview allows staff to get to know students better, and assess their interest and level of commitment to the program. At this time, staff re-emphasize the importance of committing to the program for the academic year and explore any concerns students may have about joining.

## 2. Student Orientation

- The **Informed Consent** is reviewed and signed by each student prior to participation.
- A **3-Hour Orientation** on basic dementia information from the individual and family perspectives, communication issues and a review of all potential buddies is provided and required for all students accepted into the program. Approximately 8-12 pairs are selected and matched each year.

## 3. Match Day

- **Buddy Match Day**, a festive event over lunch is held following completion of the orientation for buddy pairs to be introduced to each other.

## 4. Program Year Activities

- Buddy pairs meet for **activities of their choosing** after ‘Match Day’. Examples of activities include visiting museums, enjoying hobbies together, exercising, shopping, or just engaging in simple conversation over a meal or coffee. The buddies are expected to commit 4 hours a month to spending time together. This can mean spending an afternoon together or meeting multiple times for shorter get-togethers. Students are required to submit activity reports following each meeting with their buddy. Program staff maintain regular contact with mentors and families to monitor their experience with the program and to trouble shoot any problems that may arise.
- Students meet with program staff monthly for hour-long discussion of their experiences with their buddies. After the first couple of monthly meetings, education topics are included in these sessions.
- At the last monthly session (April) students take post-tests of dementia knowledge and attitudes.

## 5. End-of-Year Gathering

- An End-of-the-Year-Gathering brings all the buddy pairs together to celebrate the friendships made. Some students continue to meet with their buddies; however, typically less frequently due to the heightened intensity of medical school.
- Interested mentors who continue to meet participant criteria may be re-matched with another student the following year.

## **PARTICIPANT CRITERIA**

### **FIRST YEAR MEDICAL STUDENTS**

The program directors emphasize the requirements of the program throughout the recruitment process so that students can adequately evaluate their ability to participate. The requirements are listed below:

### **PROGRAM REQUIREMENTS FOR STUDENTS**

- Attendance at all orientation sessions
- Pre and Post knowledge testing
- Attendance at “Match Day”
- Spending four face-to-face hours a month with buddy from October-May
- Monthly hour-long meeting with program staff
- Activity reports following each meeting with their buddy
- End-of-the-year reflection paper
- End-of-the-year gathering

During the interview process, students are asked to consider the time commitment and assess if they will be able to meet the program requirements.

Over the course of the year, if students cannot meet these requirements, a meeting will be requested with program staff to ascertain the reason for the difficulty and arrive at solutions. Although infrequent, from time-to-time, students have needed to withdraw from the program for a variety of academic and personal reasons. Re-emphasizing the importance of the commitment throughout orientation may help students realize their responsibility to the patient, family, and the program.

### **RECRUITMENT OF DIAGNOSED INDIVIDUALS**

Diagnosed individuals are recruited from the Neurobehavior and Memory Clinic at Northwestern. Clinical staff are aware of program criteria, and refer potential individuals to program staff for an interview. These individuals have all completed a thorough diagnostic evaluation for cognitive impairment and have received a diagnosis of Alzheimer’s disease or related disorder, such as dementia with Lewy bodies, vascular cognitive impairment, or primary progressive aphasia.

Criteria for program inclusion are:

- Documented diagnosis of a dementia in the early stage. Consideration is given to the individual’s Mini-Mental Status Examination (MMSE) score (Folstein, Folstein, & McHugh, 1975), functional level as reported by the person with dementia and family and a determination on the Clinical Dementia Rating Scale (Hughes, Berg, Danzinger, Coben, & Martin, 1982);
- The ability to demonstrate an understanding of the basic concept of the program and willingness to spend a minimum of time each month with a medical student;

- Be free of significant behavioral problems that would make it difficult to engage in an activity with a buddy;
- Ability to converse adequately to convey and comprehend a verbal message;
- Sufficient hearing;
- Being free of functional impairments that would require assistance or supervision (i.e., assistance with toileting);
- Live within a certain geographic distance (determined by the student) that is accessible and not burdensome for the students. Some families have chosen to provide transportation for the patient to the medical school.
- Have a family member or friend who can be involved in the program and contacted in case of emergency.

Interviews are required to ensure that participant criteria are met, and that diagnosed persons and families understand the expectations of the program. During the interview, participation requirements are discussed. It is also during this time that staff learn of any buddy preferences; that is, for a specific gender, for someone who speaks a specific second language, interest in the arts or sports) Selected diagnosed individuals and families are provided with written material about the Buddy Program at the beginning of the program each year.

#### **PROGRAM REQUIREMENTS FOR DIAGNOSED INDIVIDUALS**

- Spending four face-to-face hours a month with the student buddy from October – May.
- If families live far from the medical school campus, we assess their flexibility regarding travel options to see their buddy. For example, is it possible to take turns visiting one another or meet half-way.

## **STUDENT ORIENTATION**

Orientation sessions are designed to educate and prepare the students to build a relationship with a person with dementia. There is a required series of three hour-long orientation sessions led by the CNADC faculty. The orientation covers the etiology, progression and treatment of dementia, as well as practical information on communication, caregiving, and the subjective experience of dementia via readings and video. The curriculum also includes an overview of family issues. During orientation, vignettes of the participating senior buddies are described to students to aid in the matching process. Lunch is provided to students at each of the orientation meetings, and the meetings are scheduled around their first year exams.

Throughout orientation, (and over the course of the year) the students have the opportunity to visit the Neurobehavior and Memory Clinic, various laboratories, and meet the staff – neurologists, neuropsychologists, psychiatrists, geriatricians, social workers, therapists, and research technicians.

Before the first orientation session begins – students complete a Dementia Knowledge Pre-test (Morhardt, 2006).

## **ORIENTATION CURRICULUM**

### **ORIENTATION #1**

*“Introduction to Alzheimer’s Disease and Related Dementias”*

The basics of Alzheimer’s disease and related dementias is presented. Typically a behavioral neurologist or neurology fellow lectures and leads discussion with the students around this topic.

### **ORIENTATION #2**

*“Good Buddy Communication” and “Dementia and the Family”*

This meeting reviews the importance of good communication with buddies and family members and the impact of the diagnosis on the family. At this meeting, we also discuss possible Buddy activities, what has worked well in the past with previous Buddy pairs and what kinds of activities to potentially avoid. This topic is typically presented by a social worker.

### **ORIENTATION #3**

*“Buddy Match Discussion”*

Program staff have learned that presenting buddy profiles to students and getting their feedback on who they think would be a good match is a successful strategy for making the best matches.

The 3rd orientation session is a discussion of the diagnosed persons with whom the students will be matched. These descriptions are created by staff and include information about the person, their former career, their diagnosis, their interests and hobbies, and relevant information about caregivers/family members. After hearing about the senior buddies, students select 3 diagnosed individuals with whom they believe they would like to be matched for the school year. Directors do their best to match pairs based upon student (and senior buddy) preference, compatibility of interests, logistical concerns and demographic preferences. The process of matching also includes asking the person with dementia their preferences regarding a buddy in terms of personality style and gender.

*Examples of vignettes:*

*Gary is a 76 year-old male who lives with his wife in downtown Chicago. He was raised on a farm in Georgia and moved to Chicago when he was 22 years old. He worked in advertising for 45 years until he retired due to the early symptoms of AD. He is an avid Cubs fan and enjoys watching and discussing his favorite team.*

*Glenn has 3 children and 5 grandchildren who all live locally. He enjoys going to the theater and baseball games, taking walks along the lake and discussing politics. He has been a collector of rare stamps from all over the world and enjoys sharing his collection with others.*

## **THE YEAR BEGINS**

### **MATCH DAY**

A 'Match Day' is held at the end of September or early October. The Match Day is a festive event around a luncheon that brings the diagnosed individuals, their families, students, and center staff together. Here, the buddies meet each other for the first time. Family members also get to know the student, as they often facilitate the buddy visits.

To help acquaint the buddy pairs with each other, the students are provided with a "Getting To Know You" questionnaire, which they work on with their buddy for 15–20 minutes. During the getting to know you questions, they discover common likes and interests and decide to meet in the coming weeks to enjoy an activity together.

Following the conversation time, each student introduces his or her buddy to the group and presents what they learned about their buddy.

Photographs are taken at this event of each buddy pair. They are then placed in a frame with the words – "This is my buddy, Joe" for example, and given to both the student and diagnosed person as a memento of their program experience. This also serves as a visual cue for persons with dementia.

### **GETTING TOGETHER**

The time and place of meetings, and appropriate buddy activities are determined by the person with dementia, the family, and the student. Buddy pairs are provided with a handout of ideas of local things they might do together. The staff are also available for suggestions.

### **MONTHLY PROCESS MEETING WITH STUDENTS**

In addition to the 4 hours spent with their buddies, the students are required to attend hour-long monthly process meetings. These meetings are facilitated by CNADC staff and provide students an opportunity to share how things are going, ask questions about the disease, express any concerns they have and receive guidance and support. Based upon the student's interest, educational presentations by CNADC clinicians and other invited speakers are scheduled during these meetings.

### **CLINICAL OPPORTUNITES**

If agreed upon by the buddy and arranged by the Neurobehavior and Memory Clinic, students may have the opportunity to accompany their buddy to their scheduled clinic appointment. These visits give students an opportunity to observe neurological, neuropsychological, and/or psychiatric assessments.

At the CNADC, students also have the opportunity to be involved in observation of clinical work and discussion of patient diagnostic evaluations at weekly interdisciplinary rounds.



**PROFESSIONAL GUIDANCE**

The program staff offer guidance to the students throughout the program. Staff are available to answer any questions and address concerns that might occur. This guidance is offered at the monthly process meetings, and staff are also available to students by phone or email outside of meetings, as needed.

Lunch is provided and meetings are scheduled around the student's class and exam schedules.

**END OF THE YEAR CELEBRATORY LUNCH**

The Buddy Program End of the Year Party is held in May. This date is scheduled based upon the student's class and exam schedule. In addition to inviting the Buddy pairs, family members and friends are also invited to attend. This party is a celebration of the year together and a chance for the buddy pairs to share their experiences with others. We ask pairs to share thoughts and reflections of their time together, in addition to any pictures, photos, or creations they may have crafted together. Lunch/afternoon snacks are provided at this event.

**CERTIFICATE OF COMMENDATION**

At the end of successfully completing the Buddy Program year (5 hours to the program per month coupled with the appropriate evaluation forms), each student is given a Certificate of Commendation from M.Marsel Mesulam, M.D, Director of the CNADC and the Program Director, Darby Morhardt, MSW. A letter is placed in the student's Medical School file outlining their involvement in the program and whether they met program requirements. The diagnosed person is given the same Certificate of Commendation as well.

**SPECIAL CONSIDERATIONS****WHEN BUDDY PAIRS DO NOT WORK OUT**

In the history of the program, some Buddy Pairs have not always completed the full year. For example, some students have chosen to discontinue participation during the course of the year for academic or personal reasons. Other reasons include, unexpected decline in patient's cognition and behavior that made continued visits very difficult for both the student and person with dementia. On rare occasions, the person with dementia has changed their mind about the program after initially agreeing to participate. Sometimes family's have put more pressure on the person with dementia to participate than program staff were aware or had the opportunity to fully appreciate. This has become less common as the program has evolved over the years, which we expect is due to lessons learned by program staff in assessing both students and diagnosed individuals for the program.

If a student drops out of the program mid-year, they must complete an exit interview, submit a written letter to the program director and verbally communicate to their buddy and family that they are no longer participating in the program. In these cases, staff will try and match the Buddy with a new student, however, this is not a likely possibility in the middle of the school year. If the

person with dementia discontinues mid-year, staff will try and match the student with another diagnosed individual referred to the program from the clinic. A similar process of obtaining the reasons why the diagnosed individual will not continue is conducted through discussion with the diagnosed person and their family.

### **CONTINUING RELATIONSHIPS**

While each program only runs for the student's first academic year, some buddy pairs choose to continue their relationship over the course of the student's entire medical school career. However, due to the busy medical student schedule, this is not expected, and as the end of the year approaches, putting closure on the buddy relationship is discussed.

Diagnosed individuals who want to remain in the program and continue to meet program criteria are matched with new students the next year.

While some buddies are able to remain in the program and be re-matched with a new buddy for a number of years, there comes a time when they are not able to participate due to cognitive and functional decline. Transitioning out of the program is a difficult conversation and is often more difficult for family members than the diagnosed person. Program staff meet with the family and provide them with information about community programs or other activities from which the person may find beneficial.

## **PROGRAM BUDGET**

The buddy program is sustained by a grant from the Glen and Wendy Miller Family Foundation and in part by grant AG13854 (Alzheimer's Disease Center) from the National Institute on Aging to Northwestern University.

The Buddy Program is offered free of charge to persons with dementia and their families. Diagnosed individuals are expected to cover the costs for their portion of the activities; however, if this is prohibitive, the program will cover these expenses. Student expenses are reimbursed up to \$150 a year for activity expenses such as transportation, meals, and event admission. While these funds are budgeted, frequently, the diagnosed person and family treat the student to the activity.

Program expenditures are:

- Lunch for students for 3 orientation sessions
- Lunch at each monthly meeting (7 meetings)
- Match Day Lunch and End-of-the-Year Gathering Lunch
- Photographer for both sessions

## **ADDITIONAL INFORMATION**

### **TRANSPORTATION**

Transportation to and from buddy visits is the responsibility of the student. Students should not be the passenger when the buddy or the buddy's caregiver is driving, nor should the student be in the position of transporting the person with Alzheimer's or their family member.

In some cases, diagnosed persons do not live close to the medical school. It is the understanding of the student and diagnosed person and family that they will take turns traveling to see one another.

### **ACTIVITY EXPENSES**

Expenses for activities will be the responsibility of the student at the time of the event. However, the CNADC will reimburse students on a monthly basis for any expenses they might have accrued. The CNADC reimburses up to \$150 for the entire year.

Reimbursement can only be completed if the expenses are properly recorded. Students are required to complete a standard university expense form and submit receipts to staff at the monthly program meetings.

## **PROGRAM EVALUATION**

### **INSTITUTIONAL REVIEW BOARD (IRB)**

The Buddy Program is approved by the Northwestern University Institutional Review Board-Office for the Protection of Research Subjects as a research project. Students, diagnosed individuals and family members must sign a consent form prior to their involvement in the Buddy Program to acknowledge their participation in the research.

### **PRE AND POST TESTING**

At the beginning of the first orientation session, the students are given a 33-item pre-test on the basics of ADRD and management (Morhardt, 2006). This was constructed by Darby Morhardt, MSW and then Behavioral Neurology Fellow, Gulustu Kaptanoglu, MD in 2000, following an unsuccessful search for dementia knowledge tests that incorporated more than knowledge regarding AD and included questions addressing basic attitudes and values toward persons with dementia. Later in the year, at the second to last Buddy meeting (usually in April), the students are asked to complete the same Dementia Knowledge Post test. Pre and post-test results are compared to measure the student's knowledge as a result of participating in the program.

### **ACTIVITY JOURNAL**

After each visit, the students are asked to write a summary of their buddy visit experience and keep a journal throughout the year. These confidential reports, which are sent to the program staff, not only briefly describe the activity, but also describe their buddy's mood and behavior, and the student's reflections. These journal entries have become the foundation for a qualitative analysis of the buddy program providing a richer understanding about the students' experience than the pre-and post-tests of dementia knowledge alone.

### **MID-YEAR EVALUATION CHECK-IN WITH DIAGNOSED BUDDIES**

In late January/early February of each year, the diagnosed individuals and their family members are asked to evaluate the program by completing a telephone interview and questionnaire about their experience in the program. This is an opportunity for staff to receive feedback on the program from the perspective of the diagnosed person and family. Staff are available to intervene if any problems and concerns from either the diagnosed individual or student arise.

### **END OF THE YEAR REFLECTION PAPER**

Introduced in the 2009-10 academic year and modeled after Boston University's addition to the program, students are required to write an end of the year reflection paper. They may use their activity journal entries as a guide as they reflect on their experience of getting to know someone with ADRD. They are asked to discuss how the program has affected their understanding of the diagnosed person's and families' experience, and what they hope to take from this into their future practice.

### **LONGITUDINAL FOLLOW UP**

A survey is sent to students at the end of the student's third year of medical school to understand their choice of specialty and their reflection on the contribution of the buddy program to that decision.

## **EXAMPLES OF BUDDY PAIRS**

*Ben (student) hoped to be matched with Helen after he heard her described during orientation. He was new to Chicago and was interested in meeting a Buddy who knew the city well and would enjoy sightseeing with him as he explored what the city had to offer. Helen had been in the Buddy Program before and enjoyed meeting students who she could show around the city, which had, despite her short-term memory loss, remained very familiar to her. When they first met at orientation, the two planned various outings to local museums, neighborhoods and restaurants. As they spent more time together Ben noticed Helen's lapses in memory and would bring his concerns to the monthly meetings. He was uncertain about how to respond to her repetitive stories about her family and how to correct her when she was about to get on the wrong bus home. Helen lived alone and Ben expressed concern about a time when he went to her house to meet her (at the time they had planned) and she was surprised to see him there, and at first, seemed uncertain about who he was. Ben quickly learned ways to reorient Helen to who he was and what they had planned. He got in the habit of arranging with her care manager that he would pick her up at her home and drop her off at home after their visit. Despite the cognitive changes that he saw as time passed, he was struck by how much he learned from Helen as well as her hopeful and resilient attitude about her diagnosis. They continued to both enjoy their time together, whether it was discussing art at a museum or going for a walk along the lake. Ben found ways of connecting with Helen that did not rely on memory, but focused more on the wonderful moments they shared together. Over the course of the program they created a meaningful friendship that not only changed Ben's understanding about living with AD, but also enriched Helen's experience as a teacher and mentor to a young medical student.*

## STUDENT REFLECTIONS

“The experience of being a buddy to M has been a journey that I feel very privileged to have been a part of. Although this program has ended for the year, I am sure that we will be buddies for a long time. The experience has benefited my academic career by supplementing the knowledge learned in class with real-life feelings, events, and memories. In the future, I will be able to approach dementia patients and their caregivers in a more empathetic and understanding manner”.

- Student Buddy 2010

“I think my experience with G will be invaluable in helping to connect with these patients and empathize. If nothing else this time has shown me what it is like to live with a major disease and how much it affects all parts of living. This is generalizable outside of AD. It has also showed me the importance of an active and supportive family network. No one can face an illness alone and the level of support available can have a big impact on how a patient deals with a condition. Especially in AD when the patient can't always remember the particulars of the disease, it is crucial to have someone else who can take down information and remember it for him or her. Overall, I think having my first true clinical experience be drawn from the more human side of medicine will help to color all of my experiences from now on. I hope that in the next few years I will not lose this perspective”.

- Student Buddy 2010

“I feel that in the future, when I encounter patients who may have AD, I will be much more likely to look past the disease and try to treat the person. That is, I have reinforced the perspective that one should treat the person, not the illness. I am confident that the program has provided me with the interpersonal skills to also interact with a person who may have Alzheimer's disease. That is, at times patience is a very necessary and important skill in interacting with somebody with mid-late stage Alzheimer's. Thus, I feel that I have developed a strong patience and also an appreciation for spending time with somebody who has Alzheimer's. Ultimately, I am very grateful and thankful to have participated in the Buddy Program, as it has allowed me to gain a unique perspective and see a person beyond a diagnosis or disease”.

“The Buddy program has been a memorable experience for me. I found both joy and remorse in it. My perspective about AD has changed a lot after meeting someone in real life who has the illness. I will not become a physician in the future as I am pursuing a PhD, but as a future scientist, this experience has jolted my energy spirit with how I do my AD research. There is a human face to this illness now, which I didn't envision before. As a researcher in a lab, I get caught up in the monotonous experiments from day to day. But something is different now. I feel compelled and more motivated than ever because I see the urgency”.

- Student Buddy 2010

With the increased prevalence of dementia in our population and an ever-increasing demand for specialized knowledge in dementia in physicians and other health care professionals, this program offers a successful method for strengthening that knowledge base and sensitizing future

physicians to the impact of AD and related cognitive impairment on patients and families. In addition to offering a meaningful friendship and unique education about dementia diseases, we hope this program provides medical students with an understanding of the complex lives of cognitively impaired adults, which they will carry with them in their future work as medical doctors.

For more information on starting a Buddy Program in your university or institution, please contact Darby Morhardt, MSW, LCSW at 312-908-9432 or [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu)

## **ACKNOWLEDGEMENTS**

Special thanks to

- Buddy program mentors and their families for their valuable contributions to medical student education;
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- M.-Marsel Mesulam for the original idea and his ongoing support.

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## **BUDDY PROGRAM MANUAL APPENDIX**

### **Content**

Participant Overview of Program

E-mail Blast to First Year Students

Informational Lunch Flyer

Open House Agenda

Student Application

Pre-and Post-Test Reflection Measure

Orientation Schedule

Informational Letter to Senior Buddy

Match Day Flyer

Things to Do with Your Buddy Handout

Activity Journal Template

Meeting Dates Flyer

End-of-the-Year Party Flyer

Participant Certificate Template

End of Program Year 1 Evaluation

Evaluation for Participants

Evaluation for Family Members or Friends

Consent Forms

# THE BUDDY PROGRAM

*The Buddy Program is supported by a grant from the Glen and Wendy Miller Family Foundation.*

## **Program Objectives**

- Provide an opportunity for individuals with Alzheimer's disease to mentor a first year medical student and influence their future clinical practice
- Educate medical students regarding Alzheimer's disease and related disorders and related cognitive impairment
- Improve students' communication skills and patterns when interacting with older adults and cognitively impaired patients
- Increase students' awareness of skills and strengths that remain in people with AD
- Provide the opportunity for students to see how someone with AD responds to his or her own changing abilities
- Familiarize students with care and support-related issues encountered by patients with AD and their families
- Introduce students to research and practice opportunities in neurology, geriatrics, and related fields

## **I. Time Commitment**

### **Student Requirements**

Three hours of orientation on ADRD and communication skills.

Five hours per month to the Buddy Program. Four hours are devoted to buddy activities, while the other hour is dedicated to monthly program lectures from the Neurobehavior and Alzheimer's Disease Center clinicians, and support/guidance from the Buddy Program faculty.

Written reports of activities immediately following the event to program faculty/staff.

A 'reflection' paper at the end of the year in addition to a program evaluation.

### **Diagnosed Person Requirements**

Four hours per month participating in an activity with the student. End of the year evaluation of the experience via oral interview or written survey.

The Buddy Program runs on annual intervals. Each participant is asked to commit the entire academic year (September – May) to the program.



**II. Application and Selection Process**

Students must submit an application to be considered for the program. Admittance into the Buddy Program is a selective process and students are interviewed by program faculty and staff to determine whether the student is able to make the necessary time commitment to the program.

Diagnosed persons are referred from the Memory Disorders Research Core or the Neurobehavior and Memory Clinic and are contacted by program staff/faculty to determine eligibility and interest in the Buddy Program. Interviews are held with individuals not known to program faculty/staff. All individuals must be diagnosed with Alzheimer's disease or related disorder such as Dementia with Lewy Bodies or Primary Progressive Aphasia.

**II. Institutional Review Board (IRB)**

The Buddy Program is approved by the Northwestern University Institutional Review Board-Office for the Protection of Research Subjects. Both student and diagnosed individual must sign a consent form prior to their involvement in the Buddy Program. Program faculty is conducting research on program outcomes for both the student and diagnosed person.

**III. Activities**

Meetings and appropriate activities will be determined by the diagnosed person, the family, the student, and professional staff and faculty. Appropriate activities might include: going to the movies, museums, enjoying hobbies together, exercising, shopping, or just engaging in simple conversation.

**IV. Activity Journal**

Students are required to complete a brief journal entry at the end of each activity session. Journal forms will be provided to students. Completed activity journal forms should be e-mailed to Darby Morhardt, d-morhardt@northwestern.edu.

**V. Mid-Year Evaluation**

Program staff will contact all diagnosed persons and families participating in the program for feedback on their experience with the program.

**VI. Transportation**

Transportation to/from buddy visits is the responsibility of the student. Students should not be the passenger when the buddy or the buddy's caregiver is driving, nor should the student be in the position of transporting the person with Alzheimer's or their family member.

**VII. Activity Expenses**

Expenses for activities will be the responsibility of the student at the time of the event. However, the CNADC will reimburse students on a monthly basis for any expenses they may have accrued. The CNADC is unable to reimburse tax. The CNADC will reimburse

up to \$150 for the entire year. Students are required to complete a Traveler's Expense

form and submit receipts at the monthly program meetings.

**VII. Orientation**

There will be an obligatory orientation for students. This consists of three one-hour sessions conducted by the CNADC faculty. This orientation will cover the etiology, progression and treatment of dementia, as well as practical information on communication, caregiving, and the subjective experience of dementia via readings and video.

**VIII. Matching**

Matching is based on compatibility of interests, logistical concerns, and demographic preferences. The Program faculty meet with each student individually to facilitate the best match possible. The student and individual with Alzheimer's meet at the Match Day Party.

**IX. Photographs**

Photographs will be taken of Buddy pairs at the Match Party. These photographs may be used for teaching, publications or presentations at clinical meetings. No other personal information will be included in the presentation.

**X. Clinical Opportunities**

If agreed upon by the diagnosed person and family, students will have the opportunity to accompany them to their scheduled Neurobehavior and Memory Health Service clinical appointment with their doctor. These visits provide an opportunity to observe neurological, neuropsychological, and/or psychiatric assessments. Students have the opportunity to shadow a clinician at other times throughout the year on a pre-arranged basis.

**XI. Professional Guidance**

The program faculty and staff will offer guidance throughout the program and are available to answer any questions/concerns that might occur while engaging in activities.

**XII. Certificate of Commendation**

At the end of successfully completing the Buddy Program year (5 hours to the program per month coupled with the appropriate evaluation forms), each student is given a Certificate of Completion from M.-Marsel Mesulam, M.D, Director of the CNADC and Program Director, Darby Morhardt, MSW, LCSW. A letter describing the student's participation is submitted to the student's medical school or graduate school file.

Each diagnosed person receives a Certificate of Completion from M.-Marsel Mesulam, M.D., Director of the CNADC and Program Director, Darby Morhardt, MSW, LCSW. A letter of appreciation will be submitted to all diagnosed persons and their families for their involvement in the program and their contribution to the education of their medical or graduate student buddy.

**Contact Information****Darby Morhardt, MSW, LCSW**

Research Associate Professor

Director of Education

Phone: (312) 908-9432

Fax: (312) 908-8789

d-morhardt@northwestern.edu

**Mary O'Hara, AM, LCSW**

Social Worker

Assistant Director of Education

Phone: (312) 503-0604

Fax: (312) 908-8789

m-ohara@northwestern.edu

Cognitive Neurology and Alzheimer's Disease Center  
Northwestern University Feinberg School of Medicine  
320 E. Superior Searle 11<sup>th</sup> floor  
Chicago, IL 60611  
312-908-9339  
[www.brain.northwestern.edu](http://www.brain.northwestern.edu)

*E-mail Blast to First Year Students*

**Cognitive Neurology and Alzheimer's Disease Center**  
*of the Northwestern University Feinberg School of Medicine*

## **THE BUDDY PROGRAM**

*The Buddy Program™ is a unique opportunity for medical students to build relationships with persons who have early stage Alzheimer's disease or related disorders outside of a clinical setting. In addition to getting together with your buddy, you will participate in monthly group meetings and educational seminars. After successful completion of the year-long program, each Buddy receives a certificate for their medical school records. Program expenses are compensated.*

**Please join us for Lunch and more information about this innovative and interactive research program.**

**Thursday, September 2nd, 2010 from 12:00 Noon – 1:00 PM**  
Cognitive Neurology and Alzheimer's Disease Center  
320 E. Superior, Searle Building, 11th Floor

For more information – Please see attached and check out  
<http://www.brain.northwestern.edu/education/buddy.html> and  
<http://www.wardrounds.northwestern.edu/archive/2010/spring/index.html>

RSVP to Darby Morhardt  
at 312-908-9432 or [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu)

# THE BUDDY PROGRAM

*The Buddy Program is supported by a grant from the  
Glen and Wendy Miller Family Foundation.*

**Please join us for lunch to learn about The Buddy Program,  
an innovative and interactive research program!**

**Wednesday, August 31st, 2011  
12:00 Noon – 1:00 PM**

- Would you like to get to know a person with Alzheimer's disease or related disorders and understand how they are living with daily changes?
- Are you looking for an opportunity to learn about dementia in a way you could never learn from a textbook or clinical setting?
- Would you like to learn more about cutting edge dementia research from internationally renowned researchers?

If you answered "yes" to any of the questions above, you may be interested in participating in **THE BUDDY PROGRAM.**

The Buddy Program™ is a research project of the Cognitive Neurology and Alzheimer's Disease Center and an unique opportunity for first-year medical students to build a friendship with persons who have Alzheimer's disease or related disorders outside of a clinical setting.

In addition to getting together with your buddy, you will participate in monthly group meetings and educational seminars. After successful completion of the academic year-long program, each Buddy receives a certificate. A letter from the program director is placed in the student's medical or graduate school file.

Program expenses are compensated.

**RSVP to Kristine Zachrich at [k-zachrich@northwestern.edu](mailto:k-zachrich@northwestern.edu)**

Cognitive Neurology and Alzheimer's Disease Center  
320 E. Superior Street, Searle Building, 11th Floor – Chicago, IL 60611  
[www.brain.northwestern.edu](http://www.brain.northwestern.edu)

For more information, contact Darby Morhardt at 312-908-9432 or  
[d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu).

**The Buddy Program**  
**Open House & Information Lunch**

**Agenda**

- I. Introductions – program staff and students
- II. What is the Cognitive Neurology and Alzheimer’s Disease Center?
- III. What is the Buddy Program? Review goals and criteria for program completion
- IV. YouTube Video
- V. Last year’s buddy experiences – two or three students from previous year
- VI. Provide program material for their review – include copy of application
- VII. Set up interview schedule

Following the lunch, send application via e-mail and ask they submit by certain date prior to their interview.

# THE BUDDY PROGRAM

*The Buddy Program is supported by a grant from the Glen and Wendy Miller Family Foundation.*

## STUDENT APPLICATION

Name:

Mailing Address:

Phone Number:

E-Mail:

Date of Birth:

Ethnicity:

Location of Home Town:

Place of Birth:

Marital Status:

Undergraduate Institution(s):

Undergraduate Major(s) and Minor(s):

1. Please describe any previous experience with older persons (family, friends, volunteer, etc.)
2. Please describe any previous experience with persons with Alzheimer's disease and related disorders.
3. Please tell us a little about why you are interested in being a buddy. What are your goals for this experience?
4. Please list any hobbies and interests that you would like to share with your Buddy (sports, playing cards or board games, crafts, cooking, photography, etc).
5. You will be required to travel to and from your Buddy's home. Do you have any travel restrictions which we should know about, and/or do you have access to a car?
6. Do you have a preference for a Buddy (gender, occupation, hobbies, etc.)?
7. Are you interested in observing at the Neurobehavior and Memory Clinic?
8. Do you have a preference for a time and day for visiting your buddy?
9. Is there anything else you would like to tell us about yourself as it relates to your interest in The Buddy Program™?

Please e-mail completed form to Kristine Zachrich at  
k-zachrich@northwestern.edu.  
Applications are due no later than **Tuesday, September 6th, 2011.**



# THE BUDDY PROGRAM

## Dementia Knowledge Test

Please circle the most appropriate choice.

1. The most common form of dementia in those over age 65 is
  - a. Senility
  - b. Vascular dementia
  - c. Alzheimer's disease**
  - d. Parkinson's disease
  
2. Definite diagnosis of Alzheimer's disease can be made by
  - a. Brain scans (CT/MRI)
  - b. Blood tests
  - c. Neuropsychological testing
  - d. Autopsy**
  
3. Alzheimer's disease
  - a. Is rapidly progressive and leads to death in 2-3 years
  - b. Starts only after the age of 65
  - c. Is very slow and usually takes 10-15 years from diagnosis to death**
  - d. Is called dementia with Lewy bodies in younger people
  
4. Preliminary research concerning the role of heredity in Alzheimer's disease suggests that
  - a. persons with a close relative with Alzheimer's disease have an increased risk of becoming afflicted**
  - b. Alzheimer's disease is always transmitted genetically
  - c. Alzheimer's disease is only inherited if both parents are carriers of the disease
  - d. Alzheimer's disease is not an inherited disease
  
5. People sometimes write notes to themselves as reminders. How effective is this technique for persons with Alzheimer's disease?
  - a. It can never be used because reading and comprehension are too severely impaired
  - b. It may be useful for the person with mild dementia**
  - c. It is a crutch which may contribute to further decline
  - d. It may produce permanent gains in memory
  
6. When a person with AD (middle to later stage) is agitated, the first thing to do is:
  - a. give them a medication to help calm them down
  - b. speak to the person logically and rationally

c. leave the room

**d. speak in a calm soothing voice and try to distract the person from what is agitating them**

**Please write whether the following sentences are TRUE or FALSE**

1. Dementia and Alzheimer's disease mean exactly the same thing. **False**
2. When an elderly individual starts to misplace personal belongings and forgets details, there is no need for a medical evaluation since this is normal for aging. **False**
3. Dementia is untreatable. **False**
4. Frontal lobe dementia is a subtype of Alzheimer's disease in which people have language problems. **False**
5. Dementia with Lewy bodies is associated with movement disorders and hallucinations along with cognitive impairment. **True**
6. All types of dementing disorders have a similar prognosis, none is reversible. **True**
7. Delirium is another name for dementia. **False**
8. If one of your parents has Alzheimer's disease, you have 50% chance of getting the disease. **False**
9. Memory problems are the earliest symptoms of all dementia syndromes. **False**
10. Depression can cause cognitive problems that are similar to a dementia syndrome. **True**
11. Alzheimer's Disease is a normal sign of aging. **False**
12. One cannot be diagnosed with Alzheimer's disease after the age of 85. **False**
13. Most family caregivers attempt to care for the individual with AD at home, using nursing home placement as a last resort. **True**
14. Some persons with AD suffer from depression. **True**
15. Family caregivers report a higher degree of depression and anxiety than age matched non-caregivers. **True**

16. A person with AD must be supervised at all times. **False**
17. A person with AD should not be told their diagnosis unless they ask. **False**
18. Persons who present with cognitive impairment have some type of dementia; it is a matter of differential diagnosis. **False**
19. Persons with AD lack capacity to make decisions for themselves. **False**
20. There is no treatment for Alzheimer's disease. **False**
21. People with Alzheimer's have short-term memory loss; however, often their long-term memory may be preserved for several years. **True**
22. It is a waste of time to invest in expensive tests to make a differential diagnosis, since there is no cure anyway. **False**
23. A person with AD loses their sense of humor as part of the disease process. **False**
24. All persons with AD deny their diagnosis. **False**
25. If persons with AD tried a little harder, they would probably remember things a little better. **False**
26. It is important for a person with AD to maintain a routine, because they may have difficulty dealing with change. **True**
27. Never argue with a person with Alzheimer's disease. **True**

*Thank you!*

# THE BUDDY PROGRAM

## 2011 Orientation Schedule

Lunch will be provided

### **Friday, September 16, 2011**

12:00 Noon -1:30 pm

320 E. Superior Street, Searle Building, 11th Floor, Rosenstone Library

*“Introduction to Alzheimer’s Disease & Related Dementias”*

*by Joseph Cooper, MD*

*“Caregiving for Someone with Dementia”*

*by Mary O’Hara, AM, LCSW*

### **Friday, September 23, 2011**

12:00 Noon -1:30 pm

320 E. Superior Street, Searle Building, 11th Floor, Rosenstone Library

*“Good Buddy Communication”*

*by Mary O’Hara, AM, LCSW*

*“Buddy Discussion” – Learn about the “Senior” Buddies in the program*

*For more information contact Kristine Zachrich  
at 312-908-9023 or [k-zachrich@northwestern.edu](mailto:k-zachrich@northwestern.edu)  
[www.brain.northwestern.edu](http://www.brain.northwestern.edu)*

October 13, 2010

Dear Buddy Program Participant:

Thank you for participating in The Buddy Program™ sponsored by the Northwestern University Cognitive Neurology and Alzheimer's Disease Center. We look forward to introducing you to your buddy at the Buddy Match Day Event on Friday October 29th, 2010 – 1:00 – 2:30 PM, Prentice Women's Hospital, 250 E. Superior, 2nd Floor, Conference Room K. At that time you will have the opportunity to meet and get to know your buddy after which you can arrange a mutually convenient time to get together.

Enclosed is an invitation to the event, information, which describes The Buddy Program™ in more detail and forms that ask for your consent to participate. The Buddy Program™ is not only a program that we hope provides you with an enriching experience, it is also a research project of the center. We are looking to understand what effects these kinds of programs have on all participants and allows us to communicate with your buddy over the year. Please bring these forms with you to the Buddy Program Match Day or return in the enclosed envelope.

Your participation in this program greatly contributes to the students' medical education and we appreciate your time and consideration. We hope that you enjoy getting to know your buddy over the next year and find it to be a rewarding experience.

If you have any questions, between now and Friday, October 29th, please do not hesitate to contact me at 312-908-9432.

We look forward to seeing you soon.

Darby Morhardt, MSW, LCSW  
Director, Education

Mary O'Hara, AM, LCSW  
Assistant Director, Education

# THE BUDDY PROGRAM MATCH DAY

**Friday, September 30, 2011  
12:30 – 2:30 PM**

**Northwestern Prentice Women’s Hospital  
250 E. Superior Street,  
2nd Floor, Conference Room K  
Chicago, IL**

.....

Please join us for an afternoon of good conversation, good company, and good food.

The Buddy Program is a research project of the Cognitive Neurology and Alzheimer’s Disease Center.

It is an opportunity for a person living with memory loss to mentor a first year medical student. For the medical students, it is an opportunity to connect with someone living with memory loss. The goal is to form a fun and friendly relationship.

It all begins on Match Day!

.....

**Lunch will be served. Complimentary parking provided.**

.....

**R.S.V.P.:**

Kristine Zachrich, 312-908-9023  
k-zachrich@northwestern.edu  
www.brain.northwestern.edu  
IRB #0364-013

*The Buddy Program is supported by a grant from the Glen and Wendy Miller Family Foundation*

# THE BUDDY PROGRAM

## Things to Do with Your Buddy

### CULTURE

**Discover the history of Chicago.** At the Chicago Cultural Center, you can browse an art exhibition, watch a film, and attend a lecture about our great city. On any given day, there are multiple events scheduled.

*Free, 78 E. Washington Street, [www.chicagoculturalcenter.org](http://www.chicagoculturalcenter.org).*

**See amazing masterpieces at one of the multiple art museums.** The Art Institute of Chicago houses more than 300,000 works of art. The Loyola University Museum of Art (LUMA) houses collections that represent the five major world faiths: Hinduism, Judaism, Buddhism, Christianity, and Islam. Or, browse the newer works at the Museum of Contemporary Art (MCA).

*Art Institute: Students and Seniors: \$12 (free on Thursday nights), 111 S. Michigan Avenue, [www.artic.edu](http://www.artic.edu)*

*LUMA: \$2-8 (free on Tuesdays), 820 N. Michigan Avenue, [www.luc.edu/luma](http://www.luc.edu/luma)*

*MCA: Students and Seniors: \$7 (free on Tuesdays), 220 E. Chicago Avenue, [www.mcachicago.org](http://www.mcachicago.org)*

**Experience another's culture.** The DuSable Museum of African American History, the National Museum of Mexican Art, the Oriental Institute of Chicago, and the Illinois Holocaust Museum and Education Center all have new exhibits to explore.

*DuSable: \$7-10, 740 E. 56th Place, [www.dusablemuseum.org](http://www.dusablemuseum.org)*

*Museum of Mexican Art: Free, 1852 W. 19th Street, [www.nationalmuseumofmexicanart.org](http://www.nationalmuseumofmexicanart.org)*

*Oriental Institute: Free (\$7 suggested donation), 1155 E. 58th Street, [www.oi.uchicago.edu](http://www.oi.uchicago.edu)*

*Holocaust: \$8-12, 9603 Woods Drive, Skokie, [www.ilholocaustmuseum.org](http://www.ilholocaustmuseum.org)*

### LEARN

**Become a scientist for a day.** Chicago has fantastic and easily accessible science museums. Learn about marine biology and go to the Shedd Aquarium. Or, pretend you're an astronaut and view the stars at the Adler Planetarium. See the skeleton of a T-Rex at the Field Museum or walk on an actual submarine or 727 jet at the Museum of Science and Industry.

*Aquarium: \$25, (free on Mondays and Tuesdays in Oct. and Nov.), 1200 S. Lake Shore Drive, [www.sheddaquarium.org](http://www.sheddaquarium.org)*

*Planetarium: \$8-12 (multiple free days, see website), 1300 S. Lake Shore Drive, [www.adlerplanetarium.org](http://www.adlerplanetarium.org)*

*Field Museum: \$12-15 (multiple free days, see website), 1400 S. Lake Shore Drive, [www.fieldmuseum.org](http://www.fieldmuseum.org)*

*Science and Industry: \$12-15 (multiple free days, see website), 5700 S. Lake Shore Drive, [www.msichicago.org](http://www.msichicago.org)*

# THE BUDDY PROGRAM

## *Things to Do with Your Buddy, continued*

**Listen to a lecture.** The Chicago Public Libraries host lectures and classes on topics ranging from knitting to storytelling to opera and everything in between.

*Free, various locations, [www.chipublib.org](http://www.chipublib.org)*

### EXPLORE

**Visit one of Chicago's many parks.** All are free and each has something different to offer. Try Millennium Park and visit "The Bean," or Lincoln Park and walk around the zoo.

*[www.chicagoparkdistrict.org](http://www.chicagoparkdistrict.org)*

**Experience nature.** Take a walking tour of the 385-acre Chicago Botanic Garden and see over 100,000 plants. Or, stay local and go to the Peggy Notebaert Nature Museum to check out their large exhibits of birds and butterflies.

*Chicago Botanic Garden: Free, but \$20 per car, 1000 Lake Cook Road, Glencoe,*

*[www.chicagobotanic.org](http://www.chicagobotanic.org)*

*Nature Museum: \$7-9 (free on Thursdays), 2430 N. Cannon Drive, [www.naturemuseum.org](http://www.naturemuseum.org)*

**Marvel at amazing architecture all around you.** Take a boat tour up the Chicago River and see historic buildings. Climb (by elevator!) to the top of the John Hancock building and get a birds-eye-view of Chicago. Or, stay on land and close to sea level by visiting one of two Frank Lloyd Wright houses in the city and Oak Park.

*Architecture Boat Tours: \$21-32, try [www.wendellaboats.com](http://www.wendellaboats.com), [www.architecture.org](http://www.architecture.org),*

*[www.chicagoline.com](http://www.chicagoline.com)*

*John Hancock Building: \$15, 875 N. Michigan Avenue, [www.hancock-observatory.com](http://www.hancock-observatory.com)*

*Wright Houses: \$12-15, Chicago: 5757 S. Woodlawn Avenue, Oak Park: 951 Chicago*

*Avenue, [www.gowright.org](http://www.gowright.org)*

### HEAR

**Enjoy live music.** Warm up inside the Fourth Presbyterian Church for their weekly "Noonday" concerts. Each Friday at 12:10pm, musicians from the area share their talents for forty-five minutes.

*Free, 126 E. Chestnut, [www.fourthchurch.org/noonday](http://www.fourthchurch.org/noonday)*

**Pack a picnic and attend a concert.** Millennium Park has monthly outdoor concerts during the warmer months. In the winter, carolers are around to sing your holiday favorites.

*Free, 201 E. Randolph Street, [www.millenniumpark.org](http://www.millenniumpark.org)*

### DO

**Volunteer.** Give back to the community and volunteer. Serve a meal at a homeless shelter, help beautify a park, help out a children's museum, or help shelve books in a library.



Volunteers are needed every day and your level of commitment is up to you.

*Multiple opportunities, try: [www.chicagosfoodbank.org](http://www.chicagosfoodbank.org), [www.chicagocares.org](http://www.chicagocares.org), [www.chicagoparkdistrict.org](http://www.chicagoparkdistrict.org), and [www.chicagochildrensmuseum.org](http://www.chicagochildrensmuseum.org)*

**Eat some of Chicago's finest - pizza!** Share a small pie and great conversation. It doesn't matter where you go, Giordano's, Lou Malnati's, Pizzeria Uno, or Gino's East, just enjoy!

# THE BUDDY PROGRAM

## Activity Journal Form

*Please complete this form within 24 hours of your visit and e-mail it to  
k-zachrich@northwestern.edu*

Name:

Buddy's Name:

Date of Visit:

Time of Visit (starting and end time):

Other individuals present for visit:

Any telephone contacts between visits (please give date and nature/details of call:

Activity:

Describe your Buddy's mood and behavior throughout the visit:

Describe your reactions, thoughts and feelings during the visit (please be as detailed as possible regarding your experience with your buddy):

Describe any interactions with the caregiver:

Describe any concerns that might have arisen during the visit:

Plan for your next visit:

COGNITIVE NEUROLOGY AND  
ALZHEIMER'S DISEASE CENTER  
*of the Northwestern University Feinberg School of Medicine*

.....

# THE BUDDY PROGRAM

## 2011-2012 MEETING DATES

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**MEETINGS WILL BE HELD FROM 12:00-1:00 PM**  
**LUNCH WILL BE PROVIDED**

.....

NOVEMBER 4, 2011  
DECEMBER 2, 2011  
JANUARY 6, 2012  
FEBRUARY 3, 2012  
MARCH 2, 2012  
APRIL 6, 2012  
MAY 4, 2012

If you have any questions, contact Kristine Zachrich at 312-908-9023 or  
k-zachrich@northwestern.edu

*The Buddy Program is supported by a grant from the Glen and Wendy Miller  
Family Foundation*

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320 EAST SUPERIOR STREET □ SEARLE 11 □ CHICAGO, ILLINOIS  
WWW.BRAIN.NORTHWESTERN.EDU

PLEASE JOIN US FOR

**The 2011 BUDDY PROGRAM  
END-OF-THE YEAR PARTY**

**DATE:**

Friday, May 20, 2011

**TIME:**

1:30 – 3:30 pm

**LOCATION:**

The Robert H. Lurie Medical Research Center of Northwestern University  
303 East Superior Street  
Gray Seminar Room  
Chicago, IL 60611

*Lunch will be served.*

**RSVP by May 6th, 2011 to:**

Kristine Zachrich  
k-zachrich@northwestern.edu  
312.908.9023

.....

This is a celebration of the friendships made over the year!

Please feel free to invite your friends and relatives.

We welcome any pictures, photos, artwork, and creations you and your buddy have shared and crafted together, and your stories.

*The Buddy Program™ is supported by a grant from the Glen and Wendy Miller Family Foundation.*

COGNITIVE NEUROLOGY AND  
ALZHEIMER'S DISEASE CENTER  
of the Northwestern University Feinberg School of  
Medicine

**JANE ADAMSON**

**IN RECOGNITION OF YOUR  
PARTICIPATION IN**

**The Buddy Program  
2010-2011**

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*M.-Marsel Mesulam, MD  
Director,  
Cognitive Neurology and  
Alzheimer's Disease Center*

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*Darby J. Morhardt, MSW, LCSW  
Director of Education, Cognitive  
Neurology and Alzheimer's Disease  
Center*

# THE BUDDY PROGRAM

## MEDICAL STUDENT - END OF PROGRAM YEAR 1 EVALUATION

We are evaluating the outcome of the Buddy Program. The questions below ask about your experience and your opinions about the program. Your responses are confidential and will not be shared with other participants in the program, including other students, persons with dementia or their family members.

We would appreciate if you would take a few minutes and complete the survey below. This will help us assess the effectiveness of our program, determine the short-term outcomes of our efforts and plan for future organization.

1. Your Name: \_\_\_\_\_ (optional)

2. Your Gender: M F

3. In your opinion, how much did your academic knowledge of Alzheimer's disease increase as a result of participating in the program? (For example, your knowledge may have increased in terms of understanding the biochemical and neuroanatomical pathology of AD and related disorders.)

1-----2-----3-----4-----5  
 NOT AT ALL GREATLY

4. In your opinion, how much did your knowledge of psychosocial issues increase as a result of participating in the program? (For example, your knowledge increased in terms of understanding patient and family issues and resources available to them.)

1-----2-----3-----4-----5  
 NOT AT ALL GREATLY

5. Participating in the Buddy Program resulted in an increased understanding of (please check all that apply)

- Symptoms of memory disorders
- Types of care available (home care, adult day care, nursing home care.)
- Where to refer patients with memory problems

- Aggressive behaviors
- Mood disorders
- Normal aging and memory
- Other types of aging difficulties (other health problems, hearing or vision loss, etc.)
- How to communicate with people suffering from memory disorders.
- Other:

6. Did your experience in the Buddy Program challenge any misconceptions you may have had prior to participating, either about Alzheimer's disease and dementia or about patients afflicted with these disorders?

- YES
- NO

Please explain:

7. In what ways did the Buddy Program have a positive influence on your experiences in medical school?

8. How did the program affect the way you may deal with older patients?

9. Would you (or have you) recommended this program to other students?

- YES
- NO

Why or Why not?

10. Looking back at your experience, would you choose this program again?

- YES
- NO

Why or why not?

11. What suggestions do you have for improving the program?

**Thank you for completing this form and for your participation in the Buddy Program.**



# THE BUDDY PROGRAM™

## EVALUATION FOR PARTICIPANTS

We are evaluating the outcome of the Buddy Program. The questions below ask about your experience and your opinions about the program. Your responses are confidential and will not be shared with other participants in the program, including other students, persons with dementia or their family members.

We would appreciate if you would take a few minutes and complete the survey below. This will help us assess the effectiveness of our program, determine the short-term outcomes of our efforts and plan for future organization.

1. Your Name: \_\_\_\_\_ (optional)

2. Your Gender: Male Female

3. Your Age:

4. Did you like having a medical student as a “buddy?”

Definitely Yes       Somewhat       Definitely No       Don't Know

5. What did you like most about having a buddy?

6. Is there anything you didn't like about having a buddy?

7. Did you enjoy the activities you did with your buddy?

Definitely Yes       Somewhat       Definitely No       Don't Know

7a. What did you enjoy most?

7b. Is there anything you didn't enjoy?

8. Would you recommend the buddy program to other people?

Definitely Yes       Somewhat       Definitely No       Don't Know

Why or Why not?

9. Did this program meet your expectations?

Definitely Yes       Somewhat       Definitely No       Don't Know

Please explain

10. Would you like us to pair you with a new buddy in the fall?

Definitely Yes       Somewhat       Definitely No       Don't Know

11. What suggestions do you have for improving the program?

**Thank you!**

# THE BUDDY PROGRAM

## EVALUATION FOR FAMILY MEMBERS OR FRIENDS

We are evaluating the outcome of the Buddy Program. The questions below ask about your experience and your opinions about the program as a family member or friend of a participant. Your responses are confidential and will not be shared with other participants in the program or their family members.

We would appreciate if you would take a few minutes and complete the survey below. This will help us assess the effectiveness of our program, determine the short-term outcomes of our efforts and plan for future organization.

1. Your Name: \_\_\_\_\_ (optional)
2. Your Gender: Male Female
3. Your Age:
4. Your relationship to the Buddy Program participant: \_\_\_\_\_
5. From your observation did your family member/friend like having a “buddy?”  
 Definitely Yes       Somewhat       Definitely No       Don’t Know
6. What were the highlights of the year?
7. Were there any problems or concerns?
8. What buddy activities were enjoyed most?
9. What buddy activities were enjoyed least?
10. Do you think the student buddy seemed knowledgeable about how to interact and

communicate with your family member?

Definitely Yes       Somewhat       Definitely No       Don't Know

11. Was the Buddy Program staff readily available if you had questions or problems?

Definitely Yes       Somewhat       Definitely No       Don't Know

Please explain

12. Would you recommend the Buddy Program to other people?

Definitely Yes       Somewhat       Definitely No       Don't Know

Why or Why not?

13. Did the Buddy Program meet your expectations?

Definitely Yes       Somewhat       Definitely No       Don't Know

Please explain

14. Would you like your family member to be paired with a new buddy in the fall?

Definitely Yes       Somewhat       Definitely No       Don't Know

15. What suggestions do you have for improving the program?

**Thank you!**

Buddy Program Timeline

TASKS	STAFF ASSIGNED	DATE COMPLETED	NOTES
<b>June</b>			
<ul style="list-style-type: none"> <li>• Speak with families who may transition out of program</li> </ul>			
<b>July</b>			
<ul style="list-style-type: none"> <li>• Patient recruitment</li> </ul>			
<b>August</b>			
<ul style="list-style-type: none"> <li>• Student recruitment</li> </ul>			
<ul style="list-style-type: none"> <li>• Information lunch</li> </ul>			
<ul style="list-style-type: none"> <li>• Student interviews</li> </ul>			
<ul style="list-style-type: none"> <li>• Student pre-test</li> </ul>			
<ul style="list-style-type: none"> <li>• Student Orientation</li> </ul>			
<ul style="list-style-type: none"> <li>• Orientation #2</li> </ul>			
<ul style="list-style-type: none"> <li>• Administer and grade student tests</li> </ul>			
<ul style="list-style-type: none"> <li>• Send consent forms and Match Day invite to patients and families who will join</li> </ul>			
<b>September</b>			
<ul style="list-style-type: none"> <li>• Match Day</li> </ul>			
<b>November – May</b>			
<ul style="list-style-type: none"> <li>• Student monthly meetings</li> </ul>			
<b>January</b>			
<ul style="list-style-type: none"> <li>• Phone check-in with patients and families</li> </ul>			
<b>May</b>			
<ul style="list-style-type: none"> <li>• Student post-tests</li> </ul>			
<ul style="list-style-type: none"> <li>• Certificates awarded</li> </ul>			
<ul style="list-style-type: none"> <li>• End of the Year Celebration</li> </ul>			

Additional Notes:

**Northwestern University Feinberg School of Medicine  
Cognitive Neurology and Alzheimer's Disease Center  
CONSENT FORM AND AUTHORIZATION FOR RESEARCH  
For *MEDICAL STUDENTS* or *RESEARCH SCIENTISTS***

**Title: The Buddy Program**

**Principal Investigator: Darby Morhardt, MSW, LCSW**

**Supported by: Northwestern University and the Glen and Wendy Miller Family Foundation**

You are being asked to take part in a research study. This document has important information about the reason for the study, what you will do if you choose to be in this research study, and the way we (i.e., Northwestern University) would like to use information about you.

**What is the reason for doing this study?**

You are being asked to participate in this project as a medical student or research scientist at Northwestern University's Feinberg School of Medicine. The purpose of The Buddy Program is to bring together medical students, pre/post doctoral research scientists and other allied health professional students and persons with dementia on a one-to-one, informal basis outside of the clinical setting. The Buddy Program aims to provide a mentorship opportunity for persons with Alzheimer's and related dementias and to give medical students, pre/post doctoral research scientists and other allied health professional students the unique advantage of getting to know someone with cognitive decline outside of the clinical setting.

**What you will do if you choose to be in this study?**

As a participant in this project, you will be matched with a person with a diagnosis of Alzheimer's disease or a related illness. Matching is based on compatibility of interests, logistical concerns and demographic preferences. The Program directors meet with each student or research scientist individually to facilitate the best match possible.

Your part in this study will last for one academic year (8 months). The Buddy Program will begin with 2 ninety-minute orientation meetings. You will meet your buddy at the Buddy Match Day Party. Buddy pairs should devote a minimum of 4 hours per month to buddy activities. Examples of buddy activities include visits to museums, shopping, going to the movies, or eating at restaurants. Students are required to commit an additional 1-hour per month to attend monthly program meetings. The Buddy Program concludes at the end of the academic year.

### **Selection Procedures**

Students and research scientists interested in participating in the Buddy Program must be willing to commit to the following participation criteria:

- Participate in 2 ninety-minute orientation sessions
- Devote a minimum of four hours per month to buddy activities
- Attend a one-hour monthly program meeting
- Inform program director of your planned buddy visit
- Complete a brief journal entry at the end of each activity session and submit to director within 24 hours.
- Complete two Dementia Knowledge Tests before the first orientation and at the April program meeting.
- Write a reflection paper at the end of the program year.
- Complete a program evaluation at the end of the academic year.
- Commit to participation in the Buddy Program for the academic year; September - May.
- Complete a survey on residency choice at the end of your third year of medical school. (for medical students).
- Complete a follow-up survey two years following program completion (for research scientists and other students)

If for any reason you are unable to fulfill this commitment, you are asked to notify the program directors in writing immediately.

### **What are some of the risks and discomforts that may happen to people who are in this study?**

Your participation in this study may involve the following risks:

1. You might experience some discomfort in listening to a diagnosed individual's experience with Alzheimer's disease and in attempting to establish a relationship.
2. The buddy visits will be unsupervised. The staff of the Buddy Program cannot guarantee an individual's safety during their buddy visits.

### **What are some of the benefits that are likely to come from my being in this study?**

The potential benefit to you from participation in this project includes the opportunity to learn about Alzheimer's disease in a non-clinical setting.

### **What other procedures or courses of treatment might be available to me?**

You do not have to take part in this research study.

### **Are there any financial costs to being in this study?**

Expenses for buddy activities will be the responsibility of the diagnosed individual and family. Students and research scientists are reimbursed for expenses that they accrue, up to \$150 per academic year. You will need to provide receipts for all expenses at each monthly meeting. The

Accounting Services at Northwestern University will be given your name, address, and Social Security Number in order to issue a reimbursement check. A check will be sent to you about six weeks after you have submitted your receipts. Note, all receipts must be submitted within three months of the date the expense was accrued. Diagnosed individuals are not obligated to pay for the students' portion of the activity.

**If I have questions or concerns about this research study, whom can I call?**

You can call us with your questions or concerns. If you have any illness or injury during your time on this study, you should call us promptly. Darby Morhardt, MSW, LCSW is the person in charge of this research study. You can call her at telephone 312-908-9432.

**What are my rights as a research subject?**

If you choose to be in this study, you have the right to be treated with respect, including respect for your decision whether or not you wish to continue or stop being in the study. You are free to choose to stop being in the study at any time. Choosing not to be in this study or to stop being in this study will not result in any penalty to you or loss of benefit to which you are entitled. Specifically, your choice not to be in this study will not negatively affect your class standing or present or future employment to which you are otherwise entitled.

If you want to speak with someone who is not directly involved in this research, or have questions about your rights as a research subject, please contact the Northwestern University Institutional Review Board (IRB) Office at 312-503-9338

**What about my confidentiality and privacy rights?**

We are committed to respect your privacy and to keep your personal information confidential. When choosing to take part in this study, you are giving us the permission to use your personal health information that includes health information in your medical records and information that can identify you. For example, personal health information may include your name, address, phone number or social security number.

Your health information we may collect and use for this research includes:

- Name
- Address
- Telephone number
- Date of Birth

Once we have the health information listed above, we may share it with:

Authorized members of the Northwestern University workforce, who may need to see your information, such as administrative staff members from the Office of Research, Office for Research Integrity and members of the Institutional Review Board (a committee which is responsible for the ethical oversight of the study),



Those persons who get your information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it. Some of those persons may be able to share your information with others without your separate permission.

Results of this program may be used for teaching, research, publications, or presentations at clinical meetings. If your individual results are discussed, your identity will be protected by using a study code number rather than your name or other identifying information.

The Boston University Dementia Knowledge Tests and the Reflection Essay may be shared with the Boston University PAIRS program staff who are replicating the Buddy Program and have introduced these two elements to the program. All tests and essays will be coded by number and de-identified before sharing this data.

No information about you will be shared with the Glen and Wendy Miller Family Foundation.

**Please note that:**

- You do not have to sign this consent form. If you do not, it will not affect your treatment by health care providers, or the payment or enrollment in any health plans, or affect your eligibility for benefits. However, you will not be allowed to take part in this research study.
- You may change your mind and “take back” (revoke) this consent at any time. Even if you revoke this consent, the Principal Investigator may still use or share health information that was obtained about you before you revoked your consent as needed for the purpose of this study. To revoke your consent for the use of your health information, you must do so in writing to: Darby Morhardt, MSW, LCSW, Northwestern University Cognitive Neurology and Alzheimer’s Disease Center 320 E. Superior, Searle 11-499, Chicago, IL 60611.
- Unless you revoke your consent, it will not expire.

**Optional Study Elements:**

Please initial one of the following to indicate your choice:

\_\_\_\_\_ (initial) I agree to have photographs taken of me and my buddy at the Buddy Match Party, the End of the Year Celebration and other Buddy Program sponsored events. These photographs may be used in publications or presentations at educational programs and meetings.

\_\_\_\_\_ (initial) I do not agree to have photographs taken of me and my buddy at the Buddy Match Party, the End of the Year Celebration and other Buddy Program sponsored events.

**Consent Summary:**

I have read this consent form and the research study has been explained to me. I have been given time to ask questions, and have been told whom to contact if I have more questions. I agree to be in the research study described above.

A copy of this consent form will be provided to me after I sign it.

---

Subject's Name (printed) and Signature

Date

---

Name (printed) and Signature of Person Obtaining Consent

Date

**Northwestern University Feinberg School of Medicine  
Cognitive Neurology and Alzheimer's Disease Center  
CONSENT FORM AND AUTHORIZATION FOR RESEARCH  
For PERSONS WITH ALZHEIMER'S DISEASE OR A RELATED ILLNESS**

**Title: The Buddy Program**

**Principal Investigator: Darby Morhardt, MSW, LCSW**

**Supported by: Northwestern University and the Glen and Wendy Miller Family Foundation**

You are being asked to take part in a research study. This document has important information about the reason for the study, what you will do if you choose to be in this research study, and the way we (i.e., Northwestern University) would like to use information about you and your health.

**What is the reason for doing this study?**

You are being asked to participate in this project because you have early stage Alzheimer's disease or a related illness. The purpose of The Buddy Program is to bring together medical students, pre/post doctoral research scientists and other allied health professional students and persons with dementia on a one-to-one, informal basis outside of the clinical setting. The Buddy Program aims to provide a mentorship opportunity for persons with Alzheimer's and related dementias and to give medical students, pre/post doctoral research scientists and other allied health professional students the unique advantage of getting to know someone with cognitive decline outside of the clinical setting.

**What you will do if you choose to be in this study?**

As a participant in this project, you will be matched with a medical student, pre/post doctoral research scientist or other allied health professional student. Matching is based on a compatibility of interests, logistical concerns and demographic preferences. The program directors meet with each student, research scientist, or health professional individually to facilitate the best match possible.

Your part in this study will last for 8 months. The Buddy Program will begin when you are introduced to your buddy on Buddy Match Day. Buddy pairs should devote a minimum of 4 hours per month to buddy activities. Examples of buddy activities include visits to museums, shopping, going to the movies, or eating at restaurants. The Buddy Program will conclude in May, at the end of the academic year.

Your participation in this project will last as long as you remain physically and functionally capable of participating in The Buddy Program.

You and your family member/caregiver will meet with the Director of The Buddy Program for a program screening. Screening procedures will include an interview with you and your family member/caregiver. A decision regarding your participation will be based on the following criteria.

- A complete work-up resulting in a diagnosis of Alzheimer's disease or a related disorder;
- Acknowledgment of memory loss and some degree of recognition that it may come from Alzheimer's disease or a related disorder;
- Interest/willingness to be matched with a first year medical student or research scientist; Matching is based on compatibility of interests, logistical concerns and demographic preferences. The program directors meet with each student individually to facilitate the best match possible.
- Willingness to answer questions from program director about your visit with your buddy following the activity.
- Commitment to meeting with your buddy for a minimum of 4 hours per month;
- Ability to verbally converse adequately;
- Being free of functional impairments requiring buddy assistance or supervision (i.e., assistance with toileting);
- Being free of psychiatric disabilities that would negatively affect your ability to engage in a meaningful relationship with your student buddy;
- Willingness to complete evaluation questionnaires.

At any time in the study, you may decide to withdraw from the Buddy Program. If you withdraw no more information will be collected from you.

**What are some of the risks and discomforts that may happen to people who are in this study?**

Your participation in this study may involve the following risks:

3. You may feel discomfort at revealing personal information to a medical student or research scientist.
4. The buddy visits will be unsupervised. The staff of the Buddy Program cannot guarantee an individual's safety during their buddy visits.

**What are some of the benefits that are likely to come from my being in this study?**

The potential benefit to you from participation in this project includes the opportunity to meet a medical student, pre/post doctoral research scientist or other allied health professional students on a one-to one, informal basis outside of the clinical setting. This relationship may provide you with an opportunity for social activities and develop a friendship with this individual, allowing you to share your experiences of living with Alzheimer's disease. Taking part in this project may help medical students, pre/post doctoral research scientists and other allied health professional students better understand the experience of living with memory loss and other symptoms of Alzheimer's and related illnesses.

**What other procedures or courses of treatment might be available to me?**

You do not have to take part in this research study.

**Are there any financial costs to being in this study?**

Expenses for buddy activities will be the responsibility of you or your family/caregiver. Diagnosed individuals are not obligated to pay for the medical students, pre/post doctoral research scientists and other allied health professional students' portion of the activity. You will not be paid for your participation in this study. You will not be reimbursed for your transportation expense or parking expenses you or your family member may incur.

**If I have questions or concerns about this research study, whom can I call?**

You can call us with your questions or concerns. If you have any illness or injury during your time on this study, you should call us promptly. Darby Morhardt, MSW, LCSW is the person in charge of this research study. You can call her at telephone 312-908-9432.

**What are my rights as a research subject?**

If you choose to be in this study, you have the right to be treated with respect, including respect for your decision whether or not you wish to continue or stop being in the study. You are free to choose to stop being in the study at any time. Choosing not to be in this study or to stop being in this study will not result in any penalty to you or loss of benefit to which you are entitled. Specifically, your choice not to be in this study will not negatively affect your right to any present or future medical treatment to which you are otherwise entitled.

If you want to speak with someone who is not directly involved in this research, or have questions about your rights as a research subject, please contact the Northwestern University Institutional Review Board (IRB) Office at 312-503-9338.

**What about my confidentiality and privacy rights?**

We are committed to respect your privacy and to keep your personal information confidential.

When choosing to take part in this study, you are giving us the permission to use your personal health information that includes health information in your medical records and information that can identify you. For example, personal health information may include your name, address, phone number or social security number.

Your health information we may collect and use for this research includes:

- Name
- Date of Birth
- Address
- Telephone number
- Documentation of diagnosis of Alzheimer's disease or related dementia

- Allergies
- Current and past medications or therapies
- Level of cognitive functioning

Once we have the health information listed above, we may share some of this information with the following people. Please note that any research information shared with people outside of Northwestern University and its clinical partners (or affiliates) will not contain your name, address, telephone or social security number or any other direct personal identifier unless disclosure of the direct identifier is required by law [except that such information may be viewed by the Study sponsor and its partners or contractors at the Principal Investigators office].

- Authorized members of the Northwestern University workforce, who may need to see your information, such as administrative staff members from the Office of Research, Office for Research Integrity and members of the Institutional Review Board (a committee which is responsible for the ethical oversight of the study),

Those persons who get your health information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it. Some of those persons may be able to share your information with others without your separate permission.

Results of this program may be used for teaching, research, publications, or presentations at clinical meetings. If your individual results are discussed, your identity will be protected by using a study code number rather than your name or other identifying information.

No information about you will be shared with the Glen and Wendy Miller Family Foundation.

**Please note that:**

- You do not have to sign this consent form. If you do not, it will not affect your treatment by health care providers, or the payment or enrollment in any health plans, or affect your eligibility for benefits. However, you will not be allowed to take part in this research study.
- You may change your mind and “take back” (revoke) this consent at any time. Even if you revoke this consent, the Principal Investigator may still use or share health information that was obtained about you before you revoked your consent as needed for the purpose of this study. To revoke your consent for the use of your health information, you must do so in writing to: Darby Morhardt, MSW, LCSW, 320 E. Superior, Searle 11-499, Chicago, IL 60611.
- Unless you revoke your consent, it will not expire.

**Optional Study Elements:**

Please initial one of the following to indicate your choice:

\_\_\_\_\_ (initial) I agree to have photographs taken of me and my buddy at the Buddy Match Party, the End of the Year Celebration and any other Buddy Program sponsored events throughout the year. These photographs may be used in publications or presentations at educational programs and meetings.

\_\_\_\_\_ (initial) I do not agree to have photographs taken of me and my buddy at the Buddy Match Party, the End of the Year Celebration, or any other Buddy Program sponsored events throughout the year.

**Consent Summary:**

I have read this consent form and the research study has been explained to me. I have been given time to ask questions, and have been told whom to contact if I have more questions. I agree to be in the research study described above.

A copy of this consent form will be provided to me after I sign it.

\_\_\_\_\_  
Subject's Name (printed) and Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name (printed) and Signature of Person Obtaining Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Authorized subject representative Name (printed) and Signature

\_\_\_\_\_  
Date

My authority to sign as the subject's authorized representative.

- Parent**  
 **Spouse**  
 **Legal Guardian**  
 **Authorized Agent (e.g., Health Care Power of Attorney)**

**Northwestern University Feinberg School of Medicine  
Cognitive Neurology and Alzheimer's Disease Center  
CONSENT FORM AND AUTHORIZATION FOR RESEARCH  
For FAMILY MEMBERS**

**Title: The Buddy Program**

**Principal Investigator: Darby Morhardt, MSW, LCSW**

**Supported by: Northwestern University and the Glen and Wendy Miller Family Foundation**

**Introduction**

You have been asked to take part in The Buddy Program. This document has important information about the reason for the program, what you will do if you choose to participate in this program, and the way Northwestern University would like to use information about you and your health.

**What is the reason for this program?**

Your family member is invited to participate in the Buddy Program because they have a diagnosis of Alzheimer's disease or a related condition that causes cognitive decline. The purpose of this program is to provide a unique and enriching experience to persons with early stage Alzheimer's disease and related disorders (ADRD). This study is being done to evaluate the effectiveness of The Buddy Program. You are asked to take part in this study as an informant, meaning you have a family member or close friend who is participating in the Buddy Program.

**What you will do if you choose to be in this study?**

If you choose to participate, you will be asked to evaluate your family member's experience in the Buddy Program after each activity and at the end of the academic school year (May) by completing a survey/questionnaire.

Your family member will be matched with a medical student, pre/post doctoral research scientist or other allied health professional student. Matching is based on a compatibility of interests, logistical concerns and demographic preferences. The program directors meet with each student, research scientist, or health professional individually to facilitate the best match possible.

Your and your family member's participation in this study will last for 8 months. The Buddy Program will begin on Buddy Match Day. Buddy pairs are asked to devote approximately 4 hours per month to buddy activities. Examples of buddy activities include visits to museums, shopping, going to the movies, or eating at restaurants. The Buddy Program will conclude in May, at the end of the academic year.

Your family member's participation in this project will last as long as they remain physically and functionally capable of participating in The Buddy Program.



Individuals who are interested and meet study criteria will meet with the program director and/or program staff for an in-person interview. This interview will provide an opportunity to assess each person's abilities. A decision regarding participation will be based on the following:

- A complete work-up resulting in a diagnosis of Alzheimer's disease or a related disorder;
- Acknowledgment of memory loss and some degree of recognition that it may come from Alzheimer's disease or a related disorder;
- Interest/willingness to be matched with a first year medical student or research scientist; Matching is based on compatibility of interests, logistical concerns and demographic preferences. The program directors meet with each student individually to facilitate the best match possible.
- Commitment to meeting with your buddy for approximately 4 hours per month;
- Ability to verbally converse adequately;
- Being free of functional impairments requiring buddy assistance or supervision (i.e., assistance with toileting);
- Being free of psychiatric disabilities that would negatively affect your ability to engage in a meaningful relationship with your student buddy;
- Willingness to complete evaluation questionnaires.

**What are some of the risks and discomforts that may happen to people who are in this study?**

Your participation in this program does not involve any physical risk to you.

**What are some of the benefits that are likely to come from my being in this study?**

There may be no direct benefit to your participation, however, the potential benefits to your family member from participation in this program may include a sense of belonging with others who are experiencing similar concerns.

**What other procedures or courses of treatment might be available to me?**

You do not have to take part in this research study.

**Are there any financial costs to being in this study?**

Expenses for buddy activities will be the responsibility of your family member or you. Diagnosed individuals are not expected to or obligated to pay for the student's portion of the activity. You will not be paid to participate in this study. You will not be reimbursed for your transportation or parking expenses that you or your family may incur.

**If I have questions or concerns about this research study, whom can I call?**

You can call us with your questions or concerns. If you have any illness or injury during your participation in this program, you should call us promptly. Darby Morhardt, MSW, LCSW, is the person in charge of this program. You can call her at (312) 908-9432, Monday-Friday 8-5. You can also call, Mary O'Hara, AM, LCSW at (312) 503-0604 with questions about this program.

**What are my rights as a research subject?**

If you choose to participate in this program, you have the right to be treated with respect, including respect for your decision whether or not you wish to continue or stop participating in this program. You are free to choose to stop participating in this program at any time. Choosing not to participate in this program or to stop participating in this program will not result in any penalty to you or loss of benefit to which you are entitled. Specifically, your choice not to participate in this program will not negatively affect your right to any present or future medical treatment to which you are otherwise entitled.

If you want to speak with someone who is not directly involved in this program, or have questions about your rights as a program participant, please contact the Northwestern University Institutional Review Board (IRB) Office at 312-503-9338.

**What about my confidentiality and privacy rights?**

We are committed to respect your privacy and to keep your personal information confidential. In order for you participate in this program, we will need to collect information about you. Your information we may use or share for this research includes:

- Name
- Age
- Address
- E-mail address
- Telephone number

**Once we have the information listed above, we may share it with:**

Authorized members of the Northwestern University workforce, who may need to see your information, such as administrative staff members from the Office of Research, Office for Research Integrity, and members of the Institutional Review Board (a committee which is responsible for the ethical oversight of the study),

Those persons who get your information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it. Some of those persons may be able to share your information with others without your separate permission.

Results of this program may be used for teaching, research, publications, or presentations at clinical meetings. If your individual results are discussed, your identity will be protected by using a study code number rather than your name or other identifying information.

**Please note that:**

You do not have to sign this consent form. If you do not, it will not affect your treatment by health care providers, or the payment or enrollment in any health plans, or affect your eligibility for benefits. However, you will not be allowed to take part in this program.

You may change your mind and “take back” (revoke) this consent at any time. Even if you revoke this consent, the Principal Investigator may still use or share health information that was obtained about you before you revoked your consent as needed for the purpose of this study. To revoke your consent for the use of your health information, you must do so in writing to Darby Morhardt,

MSW, LCSW, Northwestern University, Cognitive Neurology and Alzheimer's Disease Center,  
320 E. Superior, Searle 11-499, Chicago, IL 60611.

Unless you revoke your consent, it will not expire.

**Optional Study Elements:**

Please initial one of the following to indicate your choice:

\_\_\_\_\_ (initial) I agree to allow photographs or videotapes to be taken of me during Buddy Program meetings. Quotes or themes from tapes and evaluations may be used in publications or presentations at educational programs and meetings.

\_\_\_\_\_ (initial) I do not agree to allow photographs or videotapes to be taken of me during the sessions.

**Consent Summary:**

I have read this consent form and the program has been explained to me. I have been given time to ask questions, and have been told whom to contact if I have more questions. I agree to participate in the program described above. A copy of this consent form will be provided to me after I sign it.

\_\_\_\_\_  
Subject's Name (printed) and Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name (printed) and Signature of Person Obtaining Consent

\_\_\_\_\_  
Date

APPENDIX C

MATRIX QUERY THEMES VS. ATTRIBUTES

Matrix Query Themes vs Attributes

THEMES	Total	Female	Male	Prev Exp OA	No Prev Exp OA	Prev Exp AD	No Prev Exp AD	Exp Stage Early	Exp Stage Mid	Exp Stage Late	Caucasian	Asian	Hisp Ethn Yes	Hisp Ethn No	2-3 Journals	4-5 Journals	6-9 Journals
SEEING BUDDY AS MENTOR	47	20	27	43	5	18	29	30	10	7	40	7	0	47	18	13	16
FOCUS ON THE RELATIONSHIP	226	118	73	180	12	114	80	96	67	28	161	0	23	168	70	56	65
Feeling increasing comfort over time	36	17	19	35	1	20	16	19	11	6	33	3	5	31	11	9	
Feeling camaraderie/ friendship	34	25	9	34	0	24	12	18	10	6	29	5	4	30	12	12	10
Feeling enjoyment/ fun	73	46	27	69	5	47	27	36	27	10	54	19	8	65	24	26	23
Being aware of communication	44	29	15	41	4	30	14	27	10	7	37	7	3	41	18	14	12
Expressing discomfort	39	24	15	36	3	19	20	16	21	2	36	0	5	34	10	12	17
FOCUS ON THE PERSON	156	96	58	146	9	78	77	88	71	25	128	0	15	139	57	38	39
Perceiving mentor's mood	143	88	55	135	9	71	73	51	67	25	119	24	15	128	54	36	53
Feeling empathy toward mentor	13	10	3	13	0	8	5	9	4	0	11	2	0	13	3	3	7
FOCUS ON ILLNESS	124	78	43	112	9	48	75	37	58	26	108	0	7	114	41	29	51
Expressing clinical concern/ opinion	28	15	13	24	4	10	18	3	19	6	24	4	4	24	14	7	7
Expressing curiosity about disease symptoms	25	20	5	23	2	3	22	6	13	6	23	2	0	25	5	1	19
Recognizing mentor's symptoms	71	44	27	68	3	37	34	29	28	14	63	8	3	68	24	22	25
AWARENESS OF SELF	65	29	34	56	7	23	40	29	20	14	57	0	2	61	24	19	20
Experiencing a changing perspective/ attitude	50	23	27	43	7	19	31	24	16	10	44	6	2	48	20	16	14
Expressing own emotional response to mentor's symptoms	15	7	8	15	0	4	11	6	5	4	15	0	0	15	4	5	6
FOCUS ON THE CAREGIVER	60	36	24	54	8	39	22	25	26	11	50	10	3	55	20	17	23

## REFERENCES

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## VITA

Darby Morhardt, PhD, LCSW, is Research Associate Professor and the Director of the Education and Information Transfer Core for the Cognitive Neurology and Alzheimer's Disease Center (CNADC) at Northwestern University Feinberg School of Medicine. The center was designated one of 29 Alzheimer's Disease Centers by the National Institute on Aging in 1996. Dr. Morhardt holds a master's degree in social work from Jane Addams College of Social Work, University of Illinois at Chicago and completed postgraduate work in family therapy at the Institute for Juvenile Research, University of Illinois at Chicago. She received her PhD in Social Work at Loyola University Chicago.

Dr. Morhardt has 30 years of clinical experience (counseling, education and care coordination) with cognitively impaired individuals and their families. This work led to the development of support, education and social programs for persons in the early stage of dementia including the Northwestern University Buddy Program, pairing first year medical students with persons with Alzheimer's disease. In addition to studying the effectiveness of these programs, other areas of research are the experience and needs of persons and families with younger onset Alzheimer's disease, in addition to those caring for persons with non-Alzheimer's dementias, including, frontotemporal dementia (FTD) and primary progressive aphasia (PPA). She spearheaded one of the first support groups in the country for these patients and their caregivers in addition to the now annual

FTD/PPA caregiver conference, which attracts over 300 caregivers across the nation. Her honors include the MetLife Foundation Mind Alert Award for the Buddy Program in 2004 and the SeniorBridge Award for Excellence in Social Work Practice in 2007.

Dr. Morhardt is also responsible for organizing the CNADC's community education and outreach programs, including an annual Alzheimer Day each Spring. She is also working to build Alzheimer's awareness in limited English proficiency communities and currently has a grant with Chicago's Korean American community to explore their experience and needs for education and services. She is involved in building a community-academic partnership with Amani-Trinity United Health Care Corporation and seven faith-based communities on Chicago's Southside to build capacity to better understand the needs of African-American caregivers. She is one of nine faculty members on the Steering Committee for the Alliance for Research in Chicagoland Communities (ARCC), Center for Community Health within Northwestern's Institute for Public Health and Medicine. ARCC's mission is to grow equitable and collaborative partnerships between Chicago area communities and Northwestern University for research that leads to measurable improvement in community health.

