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Exploring the Differences in Autonomy for Residents with Alzheimer's Disease Between Those Living in a Special Care Unit and Those in a Residential Group Home: A Comparative Study

Michelle Mari Jensen
Augsburg College

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MASTERS IN SOCIAL WORK THESIS

Michelle Marie Jensen

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1998

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A COMPARATIVE STUDY

MICHELLE MARIE JENSEN

Submitted in partial fulfillment of
the requirement for the degree of
Master of Social Work

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

1998

MASTER OF SOCIAL WORK
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MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

Michelle Marie Jensen

has been approved by the Examining Committe for the thesis requirement for the Master of Social Work Degree.

Date of Oral Presentation: April 20, 1998

Thesis Committee:

Anthony A. Bibus III
Thesis Advisor

Daniel Edwardson
Thesis Reader

Curt Paulsen
Thesis Reader

DEDICATION

This thesis is dedicated to my parents Merle and Doug Jensen, who instilled a belief in myself and in the inherent goodness of others....who taught me I can do anything I put my mind to, and that all things under the universe are possible....who taught me to love unconditionally and to love from the heart. We love because we have been loved.

This thesis is also dedicated to the millions of individuals and families living their lives battling Alzheimer's Disease and other dementing illnesses; disease's that rob personal autobiographies and diminish the landscape of the mind. "Do not go quietly, rage, rage against the dying of the light."

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The compilation of this thesis was only possible through the support and encouragement of my thesis advisor, professors, family, and friends. My friends and colleagues at Augsburg provided humor in the stressful, panic-filled days, hugs in the sad times, and the support that comes only when people have been through the same experience together. I am eternally grateful for the gifts of friendship that have grown out of the graduate and thesis experience...especially Rachel Friesen, Deirdra Hoolahan, Andrew Klopp, Mary Holte, and Molly Cave. Also, I wanted to thank my very best friend and confidant of 10 years, Diana Ford, who had to live with me and put up with my torments of computer rage and thesis frustration; who always encouraged and lifted me up when I was crabby and inconsolable. And finally to my partner of seven years, Aaron Murphy Nasset, who has stood by me every step of the way; who believed in me when I didn't believe in myself, and who rejoiced heartily with me when I turned this thesis in!

ABSTRACT

EXPLORING THE DIFFERENCES IN AUTONOMY FOR RESIDENTS WITH ALZHEIMER'S DISEASE BETWEEN THOSE LIVING IN A SPECIAL CARE UNIT AND THOSE IN A RESIDENTIAL GROUP HOME: A COMPARATIVE STUDY

MICHELLE MARIE JENSEN

APRIL 20, 1998

Dementia of the Alzheimer's type (DAT) is a progressive, terminal disease marked by the loss of cognitive function. Due to cognitive impairments, residents with dementia exhibit behaviors that indicate disordered person in environment transactions. Due to the resulting disordered transactions, residents with dementia living in long-term care settings often experience diminished opportunity to choose.

This paper is a comparative/descriptive study based on nursing assistant responses from an anonymous questionnaire in two long-term care facilities. Autonomy is defined by Callopy (1988) as freedom, independence and choice.

The results indicate that the residents at each respective facility seem to experience autonomy in different areas, but that overall the level achieved is fairly consistent between the two. Both homes restrict autonomy, but it seems to be overshadowed by the enforcement of safety.

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I. INTRODUCTION

Dementia of the Alzheimer's Type:The Effect and Process of the Disease

Alzheimer's disease is one of the most disabling disorders of later life and is a devastating form of nonreversible dementia. Although not exclusively occurring in old age, the incidence of Alzheimer's disease increases as the person ages. Dementia of the Alzheimer's Type (DAT) is a progressive, terminal disease marked by the continual loss of cognitive function. This disease is characterized by severe, unrelenting brain atrophy and the aggregation of neurofibrillary tangles and neuritic plaques in the cerebral cortex (Blieszner & Shifflett, 1990).

The impact of the disease extends far beyond the individual who is afflicted as they place extreme burdens on both family and community. The loss of neurobehavioral function presents challenges to patients, caregivers, family systems, the health care delivery system, and society as a whole (Filley, 1995). Alzheimer's disease is the fourth leading cause of death and currently affects four million Americans (Caron, 1991). The scope of this problem is vast and will continue to expand as the people of this nation grow older and live longer. Ten percent of people over the age of 65 are reported to have DAT, and the prevalence increases substantially with age (Taft, Matthiesen, Farran, McCann, & Knafl, 1997).

Once the disease sets in, Alzheimer's offers no reprieve, stripping the victims of their humanity, dignity and long-term memories before it takes their lives. The process of the disease destroys memory first, cognition second, and physical functioning third (Caron, 1991). The disease destroys essential brain neurotransmitters and renders the victims completely dependent and vulnerable. The continual, ravaging losses of intellectual functioning result in deterioration of the person's ability to understand and decode the surrounding environment. There is no known cause, effective treatment, or cure (U.S. Congress, 1987). The family is then left to deal with the paralyzing ramifications this disease leaves behind.

Familial Impact and Institutional Living

Upon diagnosis of the disease, a myriad of decisions are presented to the family. Can I care for him/her at home? If not, where do I place my loved one, and what options are available? Caregiver burnout and stress increase and often times are overwhelming when caring for someone with dementia. Nursing homes are frequently utilized when burnout is manifested by the caregiver, even against the pleading wishes of a confused and scared loved one. The light of coherence gradually fades when Alzheimer's darkens reality.

While nursing home care can provide respite for family caregivers and meet the medical needs of the person with Alzheimer's, institutional life has its drawbacks. This study examines how staff in a nursing home and a residential care home perceive one of those drawbacks, the reduction of autonomy often concurrent with moving from home to a care facility. The research issue to be explored in this thesis surrounds the ethical complexities of providing our elders with autonomy while living in a long-term care facility.

With the growing concern surrounding Alzheimer's care, the impact of the environment contributing to quality of life for inhabitants of long-term care facilities has been examined (Schiff, 1990). The traditional long-term care facility primarily emphasizes meeting the medical needs of the resident. There is widespread agreement in the literature that living in nursing homes erodes personal autonomy. Often times the cognitively impaired residents' psychosocial needs, including but not limited to autonomy, are ignored (Weiner & Reingold, 1989). Despite the notion that the elderly with memory loss are entitled to self-determination and dignity, others invariably tend to make decisions for them (Hofland, 1988). With the expansion of the 85 year-old demographic cohort, increasing numbers of older adults will suffer from Alzheimer's disease and thus will require forms of care that have the predisposition to limit fundamental freedoms (Hofland, 1988).

Focus and Setting of Study

In this study, the researcher has attempted to assess what type of environmental setting more readily facilitates quality of life. This study focused on one indicator and definition of quality of life for long term care residents: autonomy. For the purposes of this study, autonomy is defined as choice and independence. Autonomy of residents as perceived by nursing assistants who care for them is operationalized by items on a questionnaire that participants in this study completed. For example, are residents restrained, and if so, how often?

The questionnaire will assess the perceptions that nursing assistants in both facilities have regarding residents' autonomy. Direct care staff were chosen as participants in this study because they have the most contact with and impact on a resident's opportunity to make decisions on a daily basis. These nursing assistants help residents in nearly every aspect of their lives, from bathing and dressing to eating and even going to the bathroom. Nursing assistants are an integral part of the caring spectrum for older adults.

Autonomy will be explored in and focused on two environmental settings available for housing those with DAT: a Special Care Unit located within a nursing home, and a residential setting. The special care unit is located within Minnesota Masonic Home, which is a highly recommended nursing home with a substantial waiting list for admission. There are three wings in total, and approximately 20 residents with Alzheimer's disease reside in each wing. Rakhma is the residential setting and provides alternative housing arrangements for older adults wishing to stay out of nursing homes. Rakhma has three locations in the Metro area. Each location is home to 10 residents, all of whom have some diagnosis of dementia. This study uses an exploratory design gathering data from questionnaires sent out to the nursing assistants at the respective facilities. The sample size consists of approximately 45 staff who are a mix of registered nursing assistants and non-registered caregivers as well.

Significance for Social Work

This country was built on the notion of independence, choice and freedom. "Independence is an integral part of the American value system, and is in fact a strong cultural imperative" (Namazi & Johnson, 1992, p. 18). The advancement of old age and infliction of memory loss should not erase the actualization of this American value for the elders of this country.

Social workers are employed throughout a wide range of agencies that service older adults. They are instrumental in the advocacy of autonomy for residents inhabiting long-term care facilities, whose voices often are unheard in the institutional setting. Invariably, autonomy is analogous with self-determination. In addition, a major tenet of the social work profession is predicated on the notion of self-determination for clients or patients. Neglect of this core value can result in a paternalist attitude and approach to clients (Wesley, 1996).

While little advancement has been made in altering the physical course of Alzheimer's Disease, a great deal can be done for the resident and family to maintain a high quality of life (Koff, 1986). The modification of the environment can enhance functional abilities and decrease aberrant behavior for those with memory loss. Response to the changes presented by the illness is mitigated in part by the physical and social surrounding environment (Cotrell & Schulz, 1993). Thoughtful and appropriate environmental interventions can enhance quality of life and provide dignity to elders with dementia (Kovach, Weisman, Chaudhury & Calkins, 1997). Nursing assistants, facility staff, and social workers can join with residents and family members in creating spaces for daily life where such environmental interventions will flourish.

The results of this study may add to what is already known about these environmental interventions and staff's role in implementing and supporting them. The focus is now turned to the review of the literature.

II. LITERATURE REVIEW

Conceptual Framework

The conceptual framework for this study is the person in environment interaction. This concept is used to explain the difficult and inappropriate behavior of DAT residents, as well as to predict the effects of the Special Care Unit environment and residential setting on both the cognitive and functional abilities of these residents (Swanson, Maas, & Buckwalter, 1994). The reaction to stress is not just caused from an environmental stressor, or the internal response to the stress, or a characteristic of the person. Rather, stress includes both the external demand and the internal experience of stress (Germain, 1991). There exists a dual focus on both the person and the resulting impact of the environment on the person with dementia. The progression of dementia impairs the resident's overall ability to interact successfully with the environment. Due to cognitive impairments, residents with dementia exhibit behaviors that indicate disordered person in environment transactions, including catastrophic reactions and inappropriate sexual and social behaviors (Swanson, et al. 1994). Based on the notion that these problematic interactions occur when the environmental demands exceed the resident's ability to adjust, Hall and Buckwalter (1994) formulated the Progressively Lowered Stress Threshold (PLST), to guide the design of appropriate interventions (Swanson, et al.).

The Progressively Lowered Stress Threshold (PLST) was developed to initially assist family members in making decisions about care for their loved one with dementia, and to organize their observations about the care received in a certain facility. It is now used to plan and evaluate the care provided in many settings where people with DAT are living (Hall, 1994). This framework was derived from the utilization of psychologic theories of stress, adaptation and coping abilities, in addition to behavioral research of Alzheimer's disease.

The loss of stress threshold, or the inability to deal with stress, propels the resident into becoming increasingly anxious. This can lead to a catastrophic reaction, which is an extreme over-reaction to an every day, common occurrence. A main trigger for this loss of stress threshold is misleading stimuli or inappropriate stimuli levels. The pace in nursing homes is often busy and hectic and can easily become overwhelming to the confused resident. Therefore, the impetus for problematic behavior such as catastrophic reactions may be environmentally induced. Long-term care residents experience of stress can be reduced with the modification of environmental demands, and if this is achieved, the cognitive and functional adaptive behavior of DAT residents will be promoted (Swanson, et al. 1994). Hence, a low-stimulus environmental setting may encourage better resident functioning (Namazi, 1993). When confusion arises due to overstimulation and residents act out inappropriately, their expression of autonomy is most certainly curtailed. An individual resident's own condition may be a "self-limiting" factor in their capacity to exercise autonomy, both the person and the environment play a role.

It is the role of the caregiver to modify the demands on the confused person due to their decreasing ability to adapt due to memory loss (Taft et al. 1997). Loss of cognition presents the individual with a complex evolution of deterioration in their abilities to complete simple tasks. Are nursing homes the most effective for combating the challenges inherent in providing humane care for those with DAT, and do they encourage or discourage the PLST?

Research Question

This study explores the levels of autonomy for residents with DAT living in a traditional nursing home setting as perceived by staff, and compares that with the perception of staff about autonomy for those living in a residential setting. Based on staff's responses to a questionnaire intended to gather perceptions of residents' autonomy, what type of long-term care environment more readily encourages the PLST conceptual framework and therefore fosters resident quality of life? Autonomy will be the operationalization as one component of quality of life, and will be the focus of this literature review.

There is a substantial need for research based interventions to guide caregivers as well as professionals in their efforts and provision for the highest quality of services for residents inhabiting long-term care centers (Taft et al). Very little empirical research has been done to investigate the impact of a particular design feature on individuals with dementia (Konvach, et al. 1997). The importance of the direct care staff and the environmental impact on resident autonomy will be the focus of the literature review.

Inappropriate Environmental Response for People with DAT; A Living Death

In the United States, families have often placed loved ones in long-term care facilities when cognitive impairments have become too much to manage. The irony of placement in a long-term care facility for people with Alzheimer's disease is that Alzheimer's care often is not medical; in other words, people with Alzheimer's disease need a supportive, nurturing environment that is specifically tailored to meet their psychosocial needs. They usually do not need extensive medical care found in nursing homes, other than a nurse to oversee their basic medication administration and bladder/bowel maintenance (Caron, 1991). Alzheimer's is an unraveling of the mind, not the body.

Treatment in long-term care centers has been focused on the management of undesirable behaviors through the use of psychotropic medications and restraints (Cotrell & Schulz, 1993). The literature states emphatically that residents living in a long-term care center may "receive inappropriate care that will result in excess disability and severely reduced quality of life" (Office of Technology Assessment, 1992, p. 51). This is only compounded when memory loss is added to the situation. However, the literature fails to go further in explaining what alternatives can be provided to divert the negative consequences for people when living in long-term care facilities. As the literature reports, Americans believe the ultimate defeat is being institutionalized, which is regarded by many as a "living death" (Cohen, 1988). Often, institutional life is congruent with significant loss of freedom. Moreover, Bartlet & Baum (1995) reported that 44% of all nursing home deaths occur within one month of admission.

Alzheimer residents often fail to respond to traditional nursing home interventions; in addition, some traditional environmental approaches, such as over-crowded noisy surroundings, may even instigate fear, increase frustration and threaten to reduce tolerance for stress as measured by the PLST. These reactions can cause the resident to become agitated and engage in dysfunctional behaviors (Hall, 1994). More people in a given space means more noise and more possibilities for over-stimulation to occur (Schiff, 1990). Therefore, the environment can have a direct impact on a resident's expression of "problematic" behavior. Indeed, many of problem behaviors associated with Alzheimer's disease are environmentally induced (Schiff, 1990).

Complaints and concerns from family members about the care provided for nursing home residents with dementia include:

- Nursing home staff members do not have enough time or flexibility to respond to individual needs of residents with dementia.
- Nursing home staff encourage dependency in residents by performing personal care functions for them, such as dressing and bathing, instead of taking more time and allowing them to complete the tasks independently.
- The physical environment of the majority of long-term care centers is too "institutional" and not "home-like" enough (Office of Technology Assessment, 1992).

The nursing home industry, according to the literature, is not prepared to meet the individualized needs of this group of people with memory loss (Mace, 1990). People inflicted with Alzheimer's disease, while frequently disoriented, can be lucid and very aware of the environment around them. The elderly of this country wish resoundingly to age in place, at home, and to avoid institutional care (Caron, 1991). Aging in place is the ideal situation, as home is one of the most meaningful environments in a person's life (Abraham, Onega, Chalifoux & Maes, 1994). Because home is not always an option, concern has just been gaining momentum about the quality of environments that society creates and provides for their elderly people (Cohen & Day, 1993).

Implementation of Special Care Units

Efforts have been made to respond to the special needs of residents with Alzheimer's disease. Special Care Units have been a response to the notion that individuals with Alzheimer's disease are best served within a specialized environment. The literature is prolific with studies concerning the efficacy of special care units for nursing home residents who suffer from dementia of the Alzheimer's type. However, the reported results are contradictory. These facilities, incorporated within a long-term care center, continue to be an integral piece of the caring spectrum as people with Alzheimer's disease/dementia frequently require assistance when they are no longer capable of living at home. Special Care Units have taken the cognitively impaired residents and housed them together away from the medically frail and cognitively intact. These facilities operate on the premise that residents deserve improved programming tailored to their specific needs surrounding dementia rather than those provided by the traditional long-term care facility (Weiner & Reigold, 1989). However, the focus on the environment in these settings is on the design of the physical setting rather than social surroundings (Taft et al.). In addition, SCU's are still steeped in the medical model approach and focused on meeting the medical needs of the resident.

Researchers in this area fervently debate what is "special" about SCU's. A unit may label itself as special if it provides even the smallest changes in environment or therapeutic features of the unit (Ohta & Ohta, 1988). While the concept of providing special services for this population is appealing, controlled studies to date have shown only limited beneficial outcomes (Mehr & Fries, 1995). The literature fails to research if these SCU's are any better prepared for and successful in providing residents with the opportunity for choice and independence. Systematic studies to date examining SCU and non-SCU environments have not shown that cognitive and/or functional abilities of DAT residents are improved within the SCU environments (Swansen et al.). Nor do we know whether SCU environments help foster autonomy any more readily than a regular nursing home unit. However, as we will see in the next session, autonomy is critical for residents' dignity and well-being.

Autonomy, an Expression of Dignity and Well-Being

People with Alzheimer's have seemed to be overlooked by professionals and experts in the aging field, in the fight against this brain killer. The focus of attention on this disease has not been on the individual afflicted, so how could their needs, including their most basic right to autonomy, be met? The afflicted person has been studied as a disease entity, rather than a human being who can contribute to the understanding of Alzheimer's (Cotrell & Schultz, 1993). Efforts have primarily been directed at bio-medical research looking for a cure and psychosocial efforts examining the burden of care placed on families (Peppard, 1986). What do individuals with memory loss need and want to live out their lives with the most dignity? How does the health care industry enhance and ensure their quality of life to the greatest extent possible? One possibility is to focus on autonomy, an expression of human dignity and facilitator of a sense of community for long-term care residents (Jameton, 1988). Autonomy is defined by Collopy (1988) as a cluster of notions, including self-determination, freedom, independence, and choice; in addition, ensuring autonomy is a complex ethical issue that is frequently cited in the literature as problematic in long-term care. Certainly, memory loss does not preclude any resident's right to autonomy.

Empirical studies reflect on how essential it is for residents of long-term care facilities to experience autonomy. Lieberman (1974) for example, discovered better post-institutional adjustment among elderly residents in institutions which provided the inhabitants a sense control and autonomy. Namazi (1993) concluded that residents benefit from environments which encourage autonomy, rather than passivity. Moreover, studies show that residents who have greater opportunity for choice will increase their psychological and physical status. In addition, whenever freedom of choice is limited, residents suffer from lower levels of self-esteem and psychological well-being (Namazi & Johnson, 1992). A survey given to residents of a long-term care facility reported that personal dignity and the freedom to make choices are extremely important to them (Ambrogi & Leonard, 1988). The literature also reports that the need for control expands as we age, and ironically, autonomy is often curtailed by caregivers of the elderly populations (Namazi & Johnson, 1992).

There are limited suggestions in the literature surrounding the assurance of autonomy and independence for residents with DAT, who constitute a large number of nursing home residents. Up to 75% of nursing home residents have some type of cognitive impairment (Hegeman & Tobin, 1988). Individuals with dementia should be able to make choices, depending on their functional and cognitive abilities. Moreover, the "application of autonomy for a person with DAT must be relevant to the degree of impairment and pertinent to the safety and security of both the individual and others" (Namazi & Johnson, 1992, pg. 17). Providing as many choices as possible to residents, even those as simple as when to get up in the morning, is honoring their dignity (Volicer, 1997). Studies have been done at the Corrine Dolan Alzheimer Center in Ohio that examine the influence upon residents' sense of autonomy when doors to the outside are locked. The findings indicate that residents do not necessarily want to go outside once they had the opportunity to do so (Knovach, et al.). It was having the choice that was important to them.

Ultimate Assault on Resident Autonomy

With advancing frailty, including but not limited to DAT, the literature reports that the execution of resident autonomy frequently shrinks or disappears entirely (Collopy, 1988). Considerations given to ensure the exercise of autonomy are often ignored in long-term care settings; moreover, as stated above, many aspects of nursing home living constrain personal autonomy (Wetle, Levkoff, Cwikel, Rosen, 1988).

The formerly mentioned study was focused on nursing home resident participation in medical decisions. A purposive sampling approach was used to gather information from residents inhabiting and clinicians working in nine long-term care facilities. Participants were selected from a wide array of socio-economic backgrounds. Nurses, social workers or physicians who were most familiar with the individual selected those whom they thought were most appropriate.

Random sampling was utilized when larger pools of participants were available. Guidelines given to the facilities for the study emphasized the desire to identify residents who were able and comfortable with participating in an interview. There was a deliberate effort to include residents with varying degrees of cognitive impairments so as not to focus solely on the most cognitively intact and articulate residents. A total of 232 residents were approached, and of that 89% completed the interviews. A total of 198 or 85% afforded to the researchers usable interviews. Qualitative and quantitative approaches were used in the formulation of the questionnaire and focused on residents' preferences for involvement in medical decision-making and their desire for information about medical care. Residents were asked how involved they were in their own medical care, whether this level was satisfactory or unsatisfactory to them, and who else was involved in medical decision making with them. They were also asked about their cognitive functioning, health status and level of depression. Nurses were also interviewed, and provided estimates about each resident's cognitive function, health status, and depression level. These answers were then compared and assessed for concordance between nurse and resident perceptions. Forty percent of residents reported no involvement at all in their health care decisions (Wetle, et al. 1988). This was in contradiction to what the nurses reported, as they viewed half of the residents as being completely involved in the decision making process (Wetle, et al. 1988). Executing independent health care related decisions is important to most people. No involvement in these decisions certainly indicates lower resident autonomy.

Nursing homes of this country are built on the medical model and focus on resident safety while often ignoring resident autonomy (Lidz, Fischer, Arnold, 1993). Moreover, resident dependency may stem from a rigid management, with little emphasis placed on resident decision making (Namazi & Johnson, 1992). The literature reports that sustaining any type of disability, especially a cognitive deficit, ensures that the elderly experience diminished opportunity to make choices (Cohen, 1988).

Many nursing home care providers assume that nursing home residents are incapable of making informed decisions about their personal care. This paternalistic attitude may promote incapacity and dependency (Wetle, et al.). In addition, these types of care facilities frequently offer beneficent, but paternalistic care to this society's dependent populations (Namazi & Johnson, 1992). However, while the literature reports on the nursing home as the ultimate assault on resident autonomy, it fails to pose solutions to the complex challenges around providing and ensuring it.

The literature reports that dementia caregivers are highly likely to use restraints (Coleman, 1993). Restraints are a common restriction of freedom in long-term care, and are a harsh deterrent to autonomy. Frequent chemical and physical restraints are employed to control problematic behavior in nursing homes, with an emphasis on the medical model behavior management approach. Restraints prevent people from ambulating and may protect them from injury, yet decrease their dignity (Volicer, 1997). Being tied down or being over-medicated is not conducive to autonomy. 25% to 85% of all nursing home residents are restrained at some time. Staff attitudes and low morale combined with insufficient staffing and burnout may help explain the common use of constraints (Coleman, 1993). Restraints are often the first response for aberrant behavior rather than the last resort (Lidz, Fischer, Arnold, 1993).

The majority of staff in formal institutions rarely advocate for resident autonomy because autonomy is difficult to ensure and enforce, and expensive because it requires extra caregivers (Namazi & Johnson, 1992). Many facilities are operated by budget concerns and restraints. Extra staff to help foster resident autonomy is not a first priority in the context of strict fiscal management. However, residents of long-term care facilities are not inmates; their admission to an institution should not preclude them of having decision making rights. Thoughtful and appropriate considerations must be given to balance the expression of autonomy with the guarantee of safety (Namazi & Johnson, 1992).

Direct Care Staff Influence on Autonomy

Integral to the opportunity for residents' independence and ability to make choices is nursing assistants' sensitivity about this issue. On a daily basis, these direct care staff probably have more interaction with the residents than anyone else. Nursing assistants provide as much as 90% of the care received by residents of long-term care facilities. Nationwide, more than 1 million people are employed as nursing assistants. Longevity in the career is common; many nursing assistants remain in long-term care position for years. Twenty-eight percent stay five or more years and 12.6% stay 10 or more years (Specialists in the Art of Caring, 1998, Bells International). Nursing assistants are trained in nursing homes to regard resident rights, yet the focus of this training is largely on safety and medical health (Lidz, Fischer & Arnold, 1993). Preparing direct care staff to respond to the social and psychological needs of residents in nursing homes is a missing, yet vital component of staff training (Coons, 1987).

Nursing home staff unintentionally may encourage dependence in the elderly by performing activities of daily living for them, often due to time constraints (Hofland, 1988). Moreover, the residents' attempt at independence was frequently met with resistance or ambivalence (Hofland, 1988). One study reported considerable direct reinforcement by staff for dependent behavior. Invariably, cost containment, fragmented staff training, and need for efficiency pose severe threats to resident autonomy (Hennessy, 1988).

The literature reports that staff in nursing homes view safety as being more important than autonomy (Lidz, et al.). Yet many scholars hold that both of these are important components to ensuring quality of life and should be able to co-exist. Resident autonomy becomes a "disvalue" in the midst of ensuring physical health, safety, institutional order and proficiency (Lidz, et al.). Residents who live in nursing homes are often placed under the authoritarian control of staff who view them as patients and are preoccupied with the residents physical status (Lidz, et al. 1993). Many people with DAT are forced into a physically "sick" role, even though their primary needs are psychosocial. Lidz, Fischer and Arnold (1993) report that staff enter resident rooms without knocking, use restraints over-zealously, speak badly about nonconformist residents, and they do not take the time to listen to resident wishes.

Therapeutic Milieu for Dementia Care: Modification of the Physical Environment to Enhance Autonomy and Independence

Careful physical planning of the environment for housing people with Alzheimer's can enhance mental functioning and allow individuals to function more independently (Brawley, 1992). Moreover, the enhancement of the physical environment must be used as an integral component for managing and treating this disease (Cotrell & Schulz, 1993). A therapeutic milieu is one that shifts the focus from a medical model to a social model. Board and care homes are nonmedical and are based on a social model that focuses on resident strengths and abilities, not on sickness and pathology. Impairments among the residents are de-emphasized, a new alternative to the medical model's emphasis on loss of functional and cognitive abilities. In this setting, strengths and remaining capacities are maximized. These models focus on the strengths perspective. This contemporary way of thinking has shifted away from an emphasis on deficits to a support of remaining abilities (Namazi & Johnson, 1992).

Supervision and assistance with activities of daily living are usually provided to residents, but usually not done for them to expedite the process as common in the nursing home industry (Mace, 1990). A small home setting with only 9-15 residents would inherently have a more relaxed pace, and the need for expediency would be minimized. The replication of an actual home would provide residents with an innate familiarity to their environment. A social model replication of a home environment is probably more aligned with what elders wish for than large, institutional settings that could never be mistaken for home.

The literature reports that the expression of autonomy must include personal responsibilities as a central component (Jameton, 1988). Indeed, choice and responsibility within the environmental setting are essential determinants of resident morale and life satisfaction (Namazi & Johnson, 1992). Residents are involved in the daily life of the board and care home, including light house-keeping responsibilities. It is beneficial to assess what responsibilities residents can assume even with memory loss, rather than to eliminate all responsibilities (Jameton, 1988). Involvement in personal responsibilities fosters a sense of community for the residents and provides them with more opportunity to make choices and enjoy independence. Research purports that dependency in long-term care is the direct result of environmental factors (Hofland, 1988). For example, one observational study of the types of patient behavior encouraged by nursing home staff, found the existence of direct reinforcement by staff for dependent behavior and either no response or punishment for independent behavior. (Hofland, 1988).

The following list characterizes the board and care residential model:

- small, homelike, and manageable setting with preferably no more than fifteen residents
- maximal resident autonomy and freedom
- individualization and flexibility of approaches and resident opportunities
- staff roles and approaches that respond to the special needs of the residents (Office of Technology Assessment, 1992).

Conclusion

Autonomy often times is a source of recurring and serious ethical conflicts between the frail elderly and those who care for them (Collopy, 1988). The research indicated that nursing homes are not conducive to ensuring autonomy for the residents living in these facilities. It is essential to remember that no one environment is ideal for meeting the needs of all people with dementia (Brawley, 1996). However, a small, residential setting may be more apt to provide an autonomous living environment for those with DAT. The literature reports that lack of choice invariably has a negative effect on emotional and physical well-being of nursing home residents (Hofland, 1988). Board and care homes may provide more opportunities for residents to exercise choice than traditional nursing home care. Autonomy for older adults with memory loss can be one way to enhance successful aging, which includes sustained engagement in social and productive, personal decision making activities (Rowe & Kahn, 1997). Moreover, autonomy is a key determinant of the resident's quality of life (Ambrogi & Leonard, 1988). Collopy stated that independence is a chief determinant of ethical sensitivity (Cohen, 1988). Those living in a long-term care facility are entitled to the creation of carefully designed environments that foster their independence and enable them to enjoy their full potential and capacities (Caplan, 1994).

The United States must begin to plan ahead to prepare for the baby-boom generation reaching retirement and to pro-actively address the issues of aging and long-term care needs (Hayworth Press, 1996). This means looking beyond what has been provided in traditional nursing home settings, as research in habitat design has only recently become a core element in developing ways to promote quality of life for people with dementia (Rockey, 1993). The board and care or residential home offers unlimited possibilities and may foster autonomy more readily than traditional nursing home care.

The attention is now turned to how the researcher has designed a study to help fill in the gaps about the importance of the direct care staff and environmental impact on resident autonomy. It is known that institutional care may tend to restrict autonomy to a greater degree than necessary to preserve safety. What is not sure is if changing to a home environment will make any difference in the expression of autonomy. Do staff at one facility value autonomy more than the other? According to staff, do residents appear to enjoy independence more readily at one facility?

III. METHODS

This chapter will describe the study design, who the participants of the study are, the measures and procedures utilized to gather the data, and will be followed by the data analysis procedures.

Study Design

This comparative study utilized a cross-sectional, anonymous survey design. Participants were staff caring for people with Alzheimer's disease. The study focused on one indicator of quality of life for long-term care residents, autonomy. For the purposes of this study, autonomy is defined as choice and independence.

Autonomy was explored in two environmental settings by seeking the perceptions of direct care staff in two facilities: a Special Care Unit (SCU) located within Minnesota Masonic Home, and Rakhma, a residential home care agency, composed of three adult foster care homes. Within Minnesota Masonic Home, autonomy was explored in the three existing SCU's: the North wing, the West wing and the South wing. Residents with dementia reside in each wing and are living among each other regardless of their level of affliction. Rakhma homes have three distinct, separate locations in the Metro area, and residents of these homes are all living together, regardless of their level of cognitive functioning. This comparative study will highlight the differences found between the perceptions of staff regarding resident autonomy.

This study explores the differences in autonomy for residents with DAT living in a traditional nursing home setting as perceived by staff, and compares that with the autonomy of those living in a residential setting. Based on staff's responses to a questionnaire intended to gather perceptions of residents' autonomy, what type of long-term care environment more readily encourages the PLST conceptual framework and therefore fosters resident quality of life? Autonomy will be operationalized by participants' perception of resident choice and freedom in every day life (including freedom from restraints) at the home or facility they are inhabiting. For example, question number two in the questionnaire asks how often the facility utilizes restraints to contain difficult behavior.

Participants

Direct care staff, or nursing assistants, are caregivers trained in providing supervision and assistance to people with memory loss. The researcher chose to look at the perceptions of staff rather than that of the resident's due to privacy and confidentiality issues of the residents. The residents in both facilities are vulnerable adults and may not have the ability to articulate that they do not wish to participate in a research study.

Families of the residents were not chosen as participants either due to their possibly less than objective opinion about where their mother or father lives. Families may paint a rosier picture about their parents' freedom, living environment, and state of well-being than is actually true. In addition, some families truly have no idea what happens behind the closed doors of a facility. Participation in a research study may have raised guilt and anxiety for family members who were still processing their decision to move a family member, parent, spouse, sibling, or even an adult child into a facility.

Because of their contact with residents on a daily basis and their somewhat neutral and objective opinion, nursing assistants seemed to the researcher to be the most appropriate participants. It is the researcher's opinion that the direct care staff make an enormous impact on determining a resident's quality of life. Full or part time nursing assistants who worked any of the three shifts, and who were employed at both facilities were recruited as the participants of the study. No other type of service personnel (registered nurses, social workers etc.) were included.

The demographics of the participants are heterogeneous, comprising both males and females, all races, and a wide range of ages. The only exclusion to participating in the research was if the person was from a temporary agency. The researcher included only the permanent staff, who therefore had sufficient knowledge of the day to day operations and workings of their facility. If they were from a temporary agency, they may not have been as knowledgeable of or as invested in the programming or values of the agency due to their limited and fluctuating work schedules. The sample size consists of approximately 45 nursing assistants who were given questionnaires.

Measures and Procedures

The researcher initially contacted the participants through an advertisement of the study posted throughout the wings of the nursing facility and residential homes. Then, the researcher attended the staff meetings of each facility and disseminated the surveys. The researcher compiled an anonymous questionnaire focusing on the issues surrounding autonomy for long-term care residents. The questionnaires were 4 pages in length, contained 17 questions, and consisted of both qualitative and quantitative questions. The researcher designed the questionnaire using the major themes that were discovered in the literature that were relevant to staff responsibility at their jobs. The major themes that arose in the literature in relation to resident autonomy were: restraint usage and its popularity, staff burnout and time limitations, the importance of resident involvement in the facility to foster a sense of independence and well-being, and how an over-crowded, noisy environment can contribute to aberrant behaviors. The composition of this questionnaire was guided by the conceptual framework of the PLST, as described in the chapter below and in more detail in chapter 2.

This conceptual framework results from the person in environment fit concept and is centered on the Progressively Lowered Stress Threshold. If residents are living in environments which over-extend and exhaust their ability to compensate for their losses, dysfunctional behavior may result. Functional abilities may also decline. If residents with memory loss are seen as having little control over their behaviors and act out in inappropriate ways, their opportunity for making choices in their lives will most likely be severely diminished as their stress threshold lowers.

In addition to the results gathered from the questionnaires, the researcher explored the philosophies and mission statement for each facility. This is done with the intention of assessing whether or not dignity, and specifically autonomy, are included as important components and values of the facility.

Data Analysis Procedures

How does one measure quality of life? This vague and elusive concept in this study is operationalized through the expression of resident autonomy as perceived by staff.

The encouragement or discouragement of autonomy is measured through the perception of the direct care staff. The environment is conceptualized to be all that surrounds us, yet is operationalized in this study to be the long-term care facility that the residents inhabit. This environment consists of a Special Care Unit located within a traditional nursing home, and a group residential home setting, both specializing in dementia care.

Purposeful steps have been taken by the researcher to assure ethical research methods. Coercion was relatively non-existent as the researcher used anonymous questionnaires and made sure that no identifying information would be available. The raw data will be kept in a locked cabinet, away from visibility and access. The raw data will be kept through June 1998, at which time it will be destroyed.

The level of measurement in the questionnaire is primarily ordinal. The data will be analyzed using content analysis and the quantitative excel computer program. Graphs will present the data more visually; percentages, standard deviation and averages will also be computed.

The next chapter will present the findings from these data analysis tools described above.

IV. RESULTS

Twenty six of the possible 45 participants in this study responded to the questionnaire. The return rate for this study was 58%. However, six (43%) questionnaires were returned from Minnesota Masonic Home and 20 (65%) were from Rakhma. This discrepancy of return rates is probably due to the fact that the researcher knows the staff at Rakhma and who may have been more willing to help. Before the issue of resident autonomy is explored between the two facilities, it is interesting to note that the overall average quality of life for residents at both facilities is deemed by the respondents to be very high. At Minnesota Masonic Home, quality of life was rated by the staff at a 4.3 out of five. At Rakhma, the average quality of life was rated 4.8 out of five. This may be a negligible difference. It is important to note that not all questions were answered by the respondents, and thus not all percentages were out of 100%.

Demographics of Staff

The average number of years spent working as a registered nursing assistant (NA/R) at Minnesota Masonic Home (MMH) was 8.5 years and at Rakhma the average was 10.5 years. The staff at MMH worked at that facility for an average of 2.6 years, in contrast to the staff at Rakhma where the average was 4.91 years. This could possibly show that staff turnover is less at Rakhma, that there is more longevity among the staff. However, the low return rate for Masonic Homes means the researcher cannot make any generalizations about Masonic home and the staff longevity.

At MMH, all staff are NA/R's. Most nursing home settings require staff to be registered with the state due to strict rules and regulations. At Rakhma, the staff are more varied in their training. Fourteen of the 20 were NA/R's, one was a Personal Care Attendant, four were non-certified caregivers and 1 was a college graduate. Regulations at Rakhma homes do not require a certain type of caregiver. Some homes that are licensed like Rakhma (Adult Foster Care) in the state of Minnesota will not employ NA/R's because there is not a need for their rigorous medical training. Alzheimer residents usually do not have extensive medical needs.

An important component of the staff focus on resident autonomy is job satisfaction. If staff are satisfied and rewarded by their job, they are more likely to be invested in the resident's well-being. Both facilities reported high job satisfaction. The mean at MMH was an 8.0 out of 10, and at Rakhma the mean was 9.0 out of 10. See Attachment A. The researcher inquired about what the staff enjoyed most about their work. The responses to choose from were social time with the residents, doing activities with the residents, assisting residents complete ADL's (activities of daily living e.g. dressing, bathing etc.), interacting with other staff, and other. At MMH, 50% (3) reported their most enjoyable aspect of working was the social time they spent with residents. One (17%) reported ADL's as being their most enjoyable part of work, another one respondent (16%) reported activities as their favorite, and another one (16%) reported other. At Rakhma, 64% (9) respondents reported social time with residents as their most enjoyable aspect of work, 29% (4) said ADL's and .7% (1) reported activities, 6.3% (6) left this question blank and/or did not understand the question. It is interesting to note that more staff at Rakhma (29%), where the less medical approach prevails, enjoy doing ADL's than at MMH (17%). The researcher had hypothesized that staff at Rakhma would enjoy activities and social time with residents far more than anything else. This was not the case for these respondents. See Attachment B.

The Importance of Nursing Assistants In Supporting Resident Autonomy

For the purposes of this study, autonomy is conceptually defined as choice and independence. In order for the researcher to operationalize this abstract term, residents' choice in every day life was examined. Often the onset of memory loss reduces one's life to a series of repetition and simplicity. Life consists of getting up, getting dressed, eating breakfast, taking medications, going to the bathroom, eating lunch, going to the bathroom, taking more medication, eating dinner, and going to bed. Providing as many choices as possible to residents, even those as simple as when to get up in the morning, is honoring their dignity and promotes autonomy.

Nursing assistants are involved in the daily routine of residents on a perpetual basis. As reported in the literature review, 90% of care received by residents of long-term care facilities is done by nursing assistants (Specialists in the Art of Caring, 1998, Bells International). At MMH, 50% (3) of the staff rated their role as *most critical* in shaping autonomy for the residents they care for. One (17%) believed his or her role is very critical and 33% (2) of the staff believed their role is only in the middle. Forty-five percent (9) staff at Rakhma believed their role to be the *most critical*. Thirty percent (6) believed their role is very critical, 15% (3) believe their role is in the middle. Surprisingly, 10% (2)

believed their role is among the least critical. See Attachment C. Interwoven with these statistics, is the level of importance that staff place on preserving autonomy. Eighty three percent (5) of the staff at MMH believe that preserving autonomy is very important to them. One respondent (17%) said it is only somewhat important. One cannot draw the conclusion, in direct opposition to what the literature reports, that autonomy becomes a "disvalue" in the nursing home setting. On the contrary, the vast majority of respondents at Masonic home reported that resident autonomy is very important to them. At Rakhma, 95% (19) of the staff report that preserving resident autonomy is very important to them. One (5%) said it is only somewhat important. See Attachment D. The importance of preserving resident autonomy is not met by resistance or ambivalence at either facilities as reported in the literature review. However, these results could again be the result of systematic error. Staff at Rakhma may have been more likely to report what they think the researcher wants to know because of the close working relationship between the two.

Why it Is Important for Staff to Preserve Autonomy

At MMH, one staff responded to this question by realizing we all get old and one day he/she may be this resident and "I hope my caregiver will allow me my choices and independence for as long as possible." Another staff member said that autonomy helps to build self-worth and individuality, "in today's world, we have so many choices, it is something we are used to and will feel a definite need to keep." Yet another staff said that not only does autonomy increase a resident's sense of self-esteem, but it decreases agitation and stress, and makes their job easier physically. However, supporting autonomy requires more one on one time.

At Rakhma, the major theme surrounding autonomy was quality of life issues. Staff wrote that autonomy preserves their dignity, it keeps residents in a more happy and positive state, that it is every residents' right and opportunity to exercise their need to remain as independent as possible. Autonomy also helps the resident feel secure, loved, and understood. Another wrote that basic human nature dictates that the more autonomy a person has over their own life, the happier they are. Still another said "residents with more autonomy will tend to be more active in a given environment. I believe this encourages healthy stimulation of the mind."

CHOICE SURROUNDING ACTIVITIES OF DAILY LIVING

Minnesota Masonic Home

At MMH, 100% of the respondents said residents could to bed and get up when they chose. However, most reported that this was with exceptions and only some residents had this choice. This number must be taken with a bit of caution, as the literature reported that the nursing home industry is guided by the notion of expediency and the staff seem to contradict themselves. Are the staff reporting the truth, or what they believe the researcher wants to hear? These results could be the result of systematic error. One staff member reported that most residents must be up by 8am, and that only 6-8 of the 60 residents were given an alternative. Another staff member said that most residents' wake up time has been pre-determined, unless they are having a really bad day. These residents were most likely the higher functioning and more cognitively intact. Another staff member said that residents do have the right to refuse ADL's, but throughout the day they try different times and approaches to get the ADL tasks done.

Sixty-seven percent (4) of the staff reported that residents could choose what they wanted to eat, but 33% (2) said they could not. One hundred percent of the staff said that resident's could refuse to eat entirely. Sixty-seven percent (4) of the staff reported that the residents could refuse to bathe; 33% (2) said they could not. Fifty-percent (3) said resident's could not chose which activities to participate in, and 50% (3) said they could chose which activities to participate in. See Attachment E. All three wings at MMH are left open and allow the residents to wander outside if they so desire. A circular walking path re-routes the residents back to the indoors. Sixty-seven percent (4) of the staff reported that the residents could go outdoors, yet they need some supervision from the staff to ensure safety. See Attachment F. The most important finding of this part of the study was that 60% (3) said that residents could not participate in the chores of the facility. See attachment G. As reported in the literature review, Jameton (1988) noted that the expression of autonomy must include personal responsibilities as a central component. Choice and responsibility in the environmental setting are essential determinants of resident morale and life satisfaction (Namazi & Johnson, 1992).

Rakhma Homes

Ten percent (2) of the respondents at Rakhma reported that residents can not get up when they choose. One staff member said that residents have to get up at a certain time unless they are extremely sick because the staff has certain things they must get done during the day. Ninety percent (18) of the staff said that residents can get up when they so desire. Only one respondent (5%) said residents could not go to bed when they wanted, but 95% (19) said they had their choice about when to go to bed. One staff said "we don't force them to go to bed. Sometimes, we make them warm milk if it helps them to sleep." Three and a half percent (4) of the respondents said the residents could not chose what to eat, mostly because staff usually follow a menu. However, they can usually help themselves to the contents of the refrigerator or cupboards between meal times. The kitchens are readily accesible and always open for the residents if they are hungry. Seventy-one percent (10) respondents reported that residents can chose what they want to eat at meal time. Thirty-two percent (6) respondents said residents could not refuse to eat, but more said it was the residents' choice, 68% (13) said they could refuse. 24% (4) of the staff reported that residents could not refuse to bathe. 76% (13) said residents could refuse to bathe, and some said that they will just approach them again during a later shift. 11% (2) of the staff said that residents could not help choose activities for the day; however, 84% (16) said they did have some input. See Attachment E. One staff member said it nicely, "resident autonomy here is encouraged, yet meals and activities are structured."

One staff member said that residents cannot go outside freely because of safety issues. Because the residents are vulnerable adults, it is important for staff and family that they are kept out of possibly dangerous situations. At two of the Rakhma homes, in the appropriate weather months, the doors are left open at all times, and the residents are free to walk in and out of the fenced yard as they please. One of the homes is always secured because the pathway leading outside is very uneven, and could easily be dangerous to residents. Eighty-three percent (15) of the staff said that residents can't go outside without help at the Rakhma homes. Seventeen percent (3) said they could go outside freely without any help. These staff agreed that most residents can go outside on their own, but not without at least some supervision. See Attachment F. Staff reported that 95% (18) of the residents could participate in the chores of the facility, and one (5%) said residents could not. See Attachment G. Participation in the chores and input in choosing activities for the day fosters a sense of community and well-being for the residents.

Restraint Utilization

Masonic Home

Two of the six respondents (33%) from MMH reported that restraints were used frequently, this was contrasted by the report of another two respondents (33%) who said restraints were used only sometimes. One respondent (17%) said restraint use was rarely employed, and another one (17%) said the facility used restraints occasionally. See Attachment H. The average for this question was 2.7, and falls between rarely and sometimes, leaning more heavily towards sometimes. As reported in the literature, staff attitudes and low morale combined with insufficient staffing may explain the common use of restraints.

When responding to what conditions warrant restraints, the prevailing theme was safety. One staff said depression, behavior such as hitting out, refusing all attempts to provide care and not eating warranted restraint use. Another wrote about the possibility of a confused resident climbing over or falling through side rails on the bed; this would unequivocally require restraints. If a resident falls all the time and is constantly harming other residents, the respondents from Masonic Home indicated that restraining the resident was justified.

When asked who decides if residents are restrained, the majority of respondents reported it is the doctor's decision, with input from the nurse and resident families.

Rakhma Homes

Two staff (11%) at Rakhma reported that restraints are never used. The majority of staff (8) reported that restraints were used rarely (41%). Sixteen percent (3) of the staff reported restraints were used sometimes, and 21% (4) of the staff said restraints were used occasionally. Eleven percent (2) of the staff reported that restraints are used frequently. See Attachment H. The mean for this group was 1.75 which falls between never and rarely, leaning heavily towards rarely. Respondents from both facilities reported on the need for more staff to ensure autonomy and decrease the need for restraints. However, as reported in the literature, resident autonomy is not a first priority in the context of strict fiscal management.

A major theme among Rakhma respondents was that aggression towards others (ATO) precipitated the use of restraints. Safety was again of paramount importance if residents run the possibility of falling out of wheel chairs or off commodes, or if they are a threat or danger to themselves or others.

At Rakhma, the staff reported that the majority of the time it is doctors who decide if residents are to be restrained.

Balancing Resident Freedom with their Safety

Masonic Home

Question number 5 (See **Appendix A**) was only answered by 67% (4) of the staff at MMH. One staff member reported that she or he balanced these often competing values by giving residents as much freedom of choice as long as they do not harm themselves. Safety takes precedence over autonomy, and this is congruent with what the literature reported. However, autonomy seems to be a value that respondents attempt to uphold. One staff member reported that guidelines for safety and autonomy are predetermined by the family, doctors, and nurses and that NA/R's are only involved in minor issues with the residents. Another staff member reported on the challenge of achieving this delicate balance, that every day is different and what is safe for one resident due to their cognitive awareness may not necessarily be safe for another.

When staff were asked what they recommend to increase residents' opportunity for choice, the results were varied. One staff member said it is important to have a group of staff who are invested in ensuring the value of autonomy and who allow residents to choose what shirt or skirt they wish to wear. The common theme for this answer consisted of having more staff and/or volunteers on hand to provide the opportunity for resident autonomy. The staff to resident ratio should be lowered they said, increasing time spent one on one with residents and thus facilitating autonomy.

Rakhma Homes

The prevailing theme from respondents at these homes was also safety. In order to keep the balance with freedom, staff wrote about the need to keep an eye on residents at all times, to supervise them closely by always being around them, and ensuring there is no eminent danger where they may be going. One staff reported that by talking to them in a calm and respectful manner, and explaining to them that they are only trying to assure their safety, she or he is balancing resident freedom with their safety. One staff said the balance was achieved by giving resident's safe choices. Yet another wrote "I believe safety is paramount, thus taking precedence over freedom. When safety is ensured and the environment is deemed safe, it is then that freedom from supervision is a priority." Moreover, another staff said that it if a resident wants to go outside when it is really cold, it is the responsibility of the staff to put boots and winter coats on them, but to let them go outside and see for themselves how cold it really is. Another staff reported that residents are to be treated as adults and given the respect they deserve. They are given complete freedom unless they are endangering themselves or others. One staff member thought it was important to do a good assessment of the resident's physical and mental capabilities at the present time and past history. For example, if the resident in the past year has had no problem going into the back yard alone for 5-10 minutes, they are probably all right to do so. As reported in the literature, it is having the choice of going outside that is important to the residents.

Restrictions to Resident Autonomy

Masonic Home

In the questionnaire, the researcher attempted to flush out the reasons why staff may be limited in ensuring autonomy for residents with memory loss. The first question of the questionnaire explored how much time on average that staff spend with residents completing ADL's, an event so steeped in providing choice on a daily basis. Entrenched in this question is the notion that the more time they spend with residents, the more the staff is probably allowing the residents to do what they can for themselves. It takes more time to allow the residents to do things for themselves, as they are often confused and slower in their motions. Less time spent with residents could correlate to staff doing the task for the resident. For example, instead of allowing them to tie their own shoe, the staff member would do it for them to save time. The data showed at MMH 67% (4 people) of the staff spend 11-20 minutes per resident helping them with ADL's. 1 staff (17%) reported spending 21-30 minutes, and another 16% (1) reported spending 31 minutes or more. This last staff member probably honors resident autonomy. See Attachment I.

When asked what takes the most time with assisting residents, one staff at MMH reported that allowing residents the opportunity to participate in doing their own ADL's takes more time. This respondent wants to keep residents functioning at least at baseline and completing some of their own cares. Going to the bathroom, doing personal cares, and assistance during meals were the examples given for what activities took the longest for staff to assist residents with.

When asked what percentage of time staff completed ADL's for the residents instead of allowing them to complete activities themselves, 33% (2) reported doing this 11-49% of the time. Fifty percent (3) reported doing this 50-75% of the time, and 17% (1) reported less than 10% of the time. See Attachment J. An outcome of staff completion of residents ADL's is the staff's unintentional encouragement of dependency by performing ADL's for residents. This dependency arises because residents begin to loose their functional abilities and begin to believe they are incapable.

As reported by the respondents, the primary reason for this assault on autonomy is time constraints. One major complaint about nursing home living from family members, as found in the literature review was time constraints. However, this was consistent between both facilities as discussed below. Although, MMH respondents seem to have less time available than Rakhma respondents, as the majority reported completing ADL's and indirectly encouraging dependency 50-75% of the time.

Another question (#7) asking how many residents staff provide direct care for on a given shift alludes to the expediency theme found in the literature. The more residents whom staff have to care for on a given shift, the less time they will have with each resident and autonomy may be curtailed. At MMH, 67% (4 staff) reported caring for 1-10 residents per shift. Seventeen percent (1) reported caring for 11-20 residents and 16% (1) reported caring for 30 or more residents. At MMH, staff to resident ratio is approximately 7:1.

The majority of staff at Masonic Home, 80% (4) reported their biggest barrier to ensuring autonomy was time constraints. Twenty percent of the staff (1) reported that the biggest barrier was feeling they could accomplish the tasks better than the resident could. None of the other factors reported in the literature were barriers to autonomy, including staff burnout. See Attachment K.

A very large barrier to ensuring autonomy is an increase in the level of confusion of the resident. One hundred percent of the staff at MMH said that people who are further advanced in the disease are less inclined to have the opportunity for choice and independence. A common theme found in this question was that the residents at this stage of memory loss have lost most of their ability to make their own decisions, often times because they are now suffering from aphasia. A Masonic Home staff member said that residents who are further advanced have less capacity for sensible choices but pose greater safety risks.

Eighty-three percent (5) staff at MMH report that ensuring resident safety is the most important thing to them, above preserving autonomy. Seventeen (1) staff reported preserving autonomy for the people they care for as the most important aspect of their job. See attachment L.

Rakhma Homes

Rakhma homes are smaller in size and capacity than MMH. At Rakhma, 100% (20) of staff reported caring for 1-10 residents per shift. This translates into a 5:1 staff to resident ratio, with more staff caring for less residents. At Rakhma, 2 staff (10%) reported spending only 5-10 minutes with residents during ADL. Six staff (30%) said they spend 11-20 minutes with residents, seven staff or 35% said they spend 21-30 minutes and 4 staff (20%) reported spending 31 minutes or more with residents. Five percent reported other. See Appendix I. When asked what takes the most time in completing ADL's, the most common response was bathing, then feeding and dressing. One staff member said the most time intensive component is allowing the resident to do things by themselves to the best of their ability, versus doing it for them to speed up the process. One might assume that when certain activities take the most time to complete, then residents experience the least choice.

Thirty percent (6) of the staff at Rakhma reported completing activities of daily living 50-75% of the time for the residents instead of allowing them to complete the activities themselves. Fifty percent (10) reported doing this 11-49% of the time and 20% (4) reported doing this less than 10% of the time. See Appendix J. The majority of staff complete resident ADL's 11-49% of the time for residents and thus encourage resident dependency. However, this is less than MMH and this could be because at Rakhma, the staff to resident ratio is lower. This translates into more staff per resident for each shift than at Masonic Home.

At Rakhma 47% (9) of the staff reported the biggest barrier to ensuring choice as being time constraints. Twenty-six percent (5) reported that the biggest barrier was feeling they could accomplish the task better than the resident. Interesting to note, in this example more staff working in a social model residential home appear more paternalistic than those working in a medical model facility setting. Twenty-two percent (4) staff responded other, and 1 staff (5%) reported safety being the biggest barrier to resident autonomy. See Attachment K.

Eighty-nine percent (17) of the staff at Rakhma said that residents who are further advanced in the disease have less opportunity for choice. However, 11% (2) of the staff said that residents who are further along in the disease process do not suffer from less autonomy. More specifically, these staff said it takes a lot of patience and time to provide residents who are further advanced in their disease with the opportunity to choose, but that they are still human beings with the fundamental right to autonomy.

At Rakhma, 73% (11) respondents reported that ensuring resident safety was most important to them. Thirteen percent (2) reported ensuring resident ADL's are met was most important, and another 13% (2) reported psychosocial needs as being the most important. No respondents at Rakhma said autonomy was number one. See Attachment L.

Methods Used to Increase Autonomy

Masonic Home

Because the nursing assistants have so much contact with residents on a daily basis, the researcher thought it was important ascertain what they recommend for increasing autonomy. A theme common to responses from Masonic Home staff was to allow the residents the opportunity to choose what they will wear for the day, and allow them to change as many times a day as they wish. Another theme centered around having more staff on hand or volunteers to pick up where staff leave off, or to have less residents to be responsible for. One staff said "the only thing in my experience that allows for greater freedom is to lower staff to resident ratios, increasing time spent one on one." Again, MMH has roughly 7 residents per one staff member.

Rakhma Homes

Consistent with respondents from MMH, those from Rakhma wrote about the need for more staff and volunteers to increase residents' opportunity for choice. For example, if a resident wants to go for a walk, is there a staff person available to go with? Staff must feel they have enough time in which to devote to dialogue and patience. Another repeating theme was to allow residents to pick out what they want to wear. The staff at Rakhma went on to say that they allow residents to make more selections at meal time, to eat what they like most, and they at least ask residents about certain situations and allow them to say yes or no. In striking contrast to the above mentioned responses, one staff member reported that it varies from individual to individual, and that choices make them more confused and only a few are capable of making choices. However, considering how residents feel about something was a predominant theme among most, not all, Rakhma staff.

Environmental Influence on Autonomy

Sixty-six percent (4) MMH respondents reported that the physical design of the facility that they work in is very important in allowing or restricting choices. One (17%) staff said it was only somewhat important, and another 17% (1) staff reported the environment has no effect at all on autonomy. At Rakhma, 70% (14) of the respondents reported that the environment is very important in allowing or restricting choice. Fifteen percent (3) staff said it was only somewhat important, and another 15% (3) said the environment has no effect on autonomy.

Sixty-seven percent (4) of the staff at MMH said that the facility they work at provides a low-stimulus environment for their residents. Thirty-three percent (2) said MMH does not. Fifty-five percent (11) of the staff at Rakhma said the home they work in provides a low-stimulus environment. Forty-five percent (9) staff reported that Rakhma is not a low-stimulus environment for the residents who inhabit the home. See Appendix M. The researcher erroneously assumed that more respondents from Rakhma would consider Rakhma a low stimulus environment. From the respondents, the researcher is more likely to conclude that residents at Masonic Home experience *less* catastrophic reactions due to a lowered PLST than at Rakhma. The Masonic Home SCU environment seems to encourage less stress for residents as measured by the respondents.

Minnesota Masonic Home Mission Statement and Philosophy

The researcher believed it was essential to examine the philosophy and mission statement for the two facilities to assess if the value of autonomy is stressed in either component and in the facility. Minnesota Masonic Home's mission statement and philosophy read like this:

Minnesota Masonic Home is dedicated to enhancing the quality of life for people served. To practice faithful stewardship, MMH will:

- be a leader in programs and services provided
- provide programs and services with integrity, dignity, and compassion

- create an environment that encourages the Masonic Home family to consistently strive for excellence

The philosophy of MMH is based on the belief that each individual is unique and is affected by physical, psychological, social, and spiritual needs. Staff work together with the resident and the resident's family to assess, plan, implement, and evaluate the individual's care, and will strive to provide quality care, growth, and fulfillment for the individual resident.

Resident quality of life is loosely referred to, and providing quality care is the closest the Mission statement comes to addressing autonomy.

Rakhma Homes Mission Statement and Philosophy

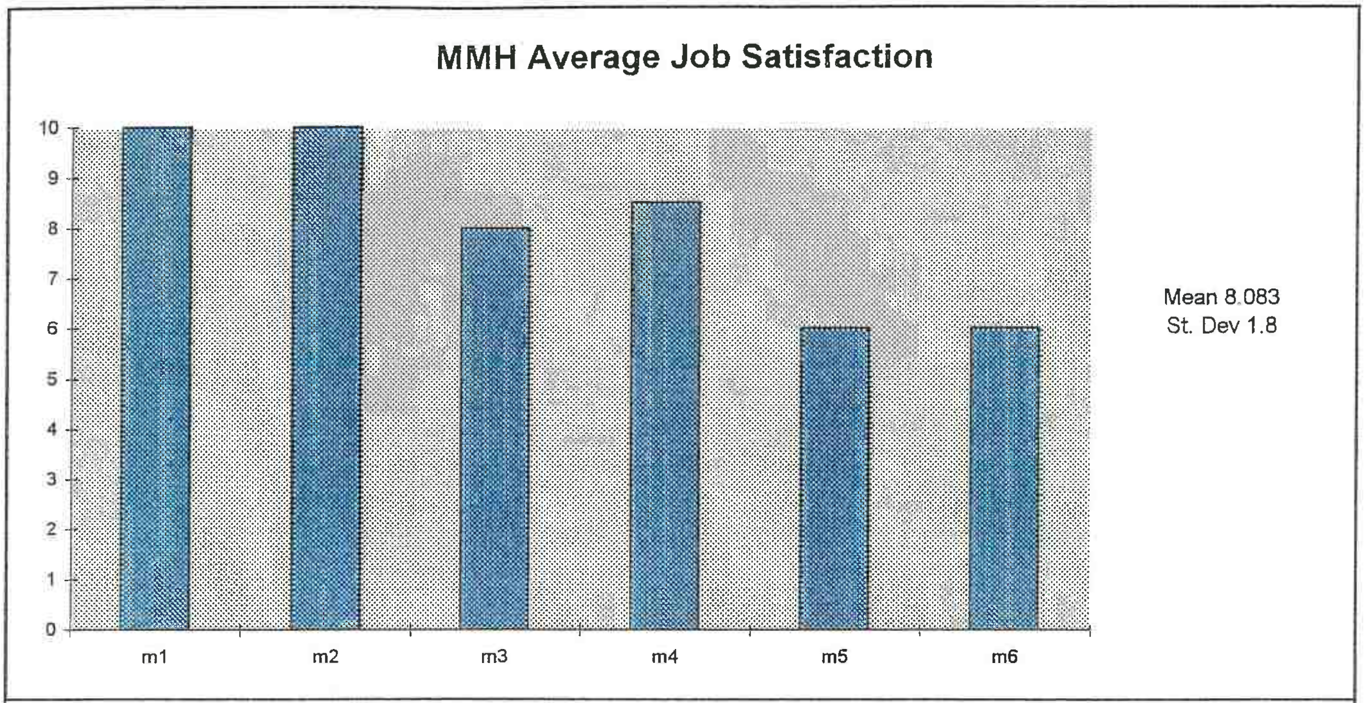
Rakhma, Inc. is a Minnesota non-profit organization which operates in accordance with state and local laws. Rakhma provides residential housing which allows people to stay in the community in a home setting. Rakhma is committed to providing alternative housing and continues to research alternative funding in order to be accessible to people of all income levels. Rakhma's approach is holistic, with an emphasis on maintaining the older person in the least intrusive manner.

Rakhma is based on a philosophy of creativity, harmony and love. Rakhma is committed to preserving the dignity of all people. Rakhma's purpose is to encourage the natural expression of joy in the lives of those we care for by providing service with a heart.

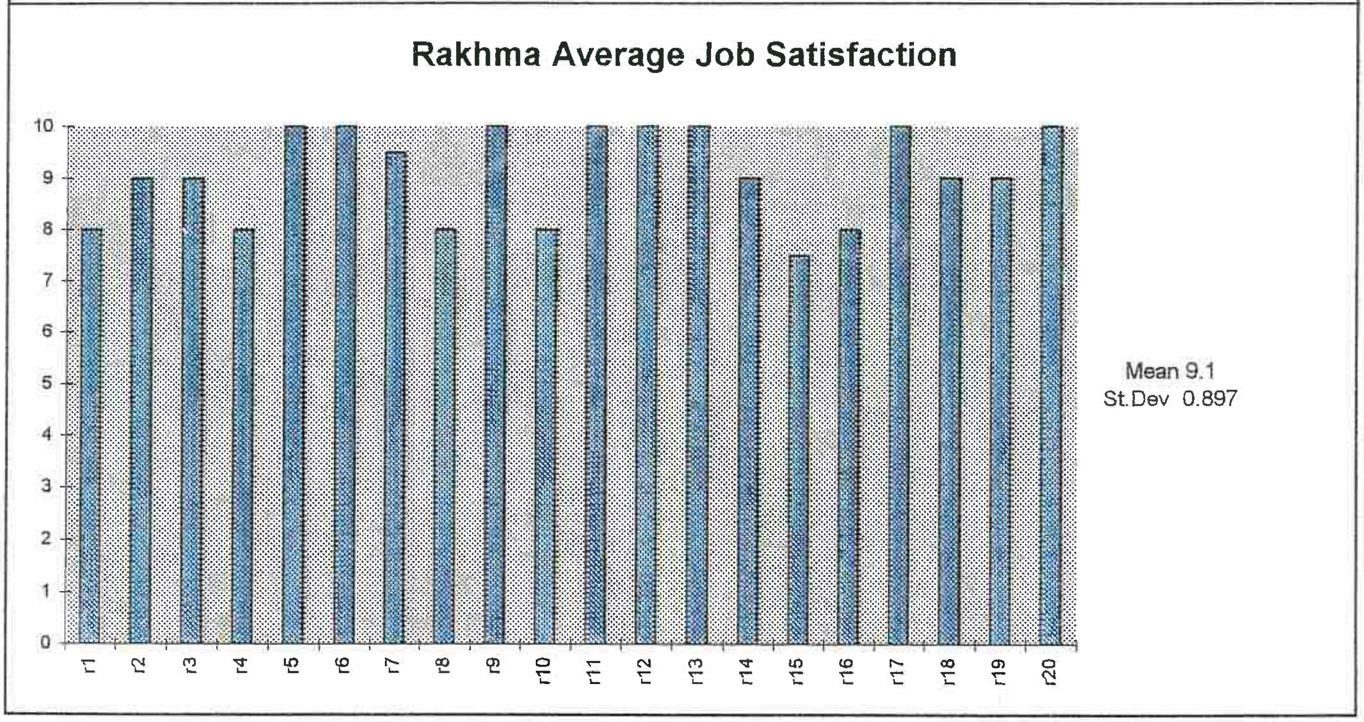
Rakhma's mission statement alludes only to autonomy by stating that it emphasized providing a least restrictive environment for the residents. The Rakhma philosophy, concurrent with MMH, briefly touches on preserving dignity for its residents.

Now the focus is turned to conclusions and implications of this study.

Attachment A

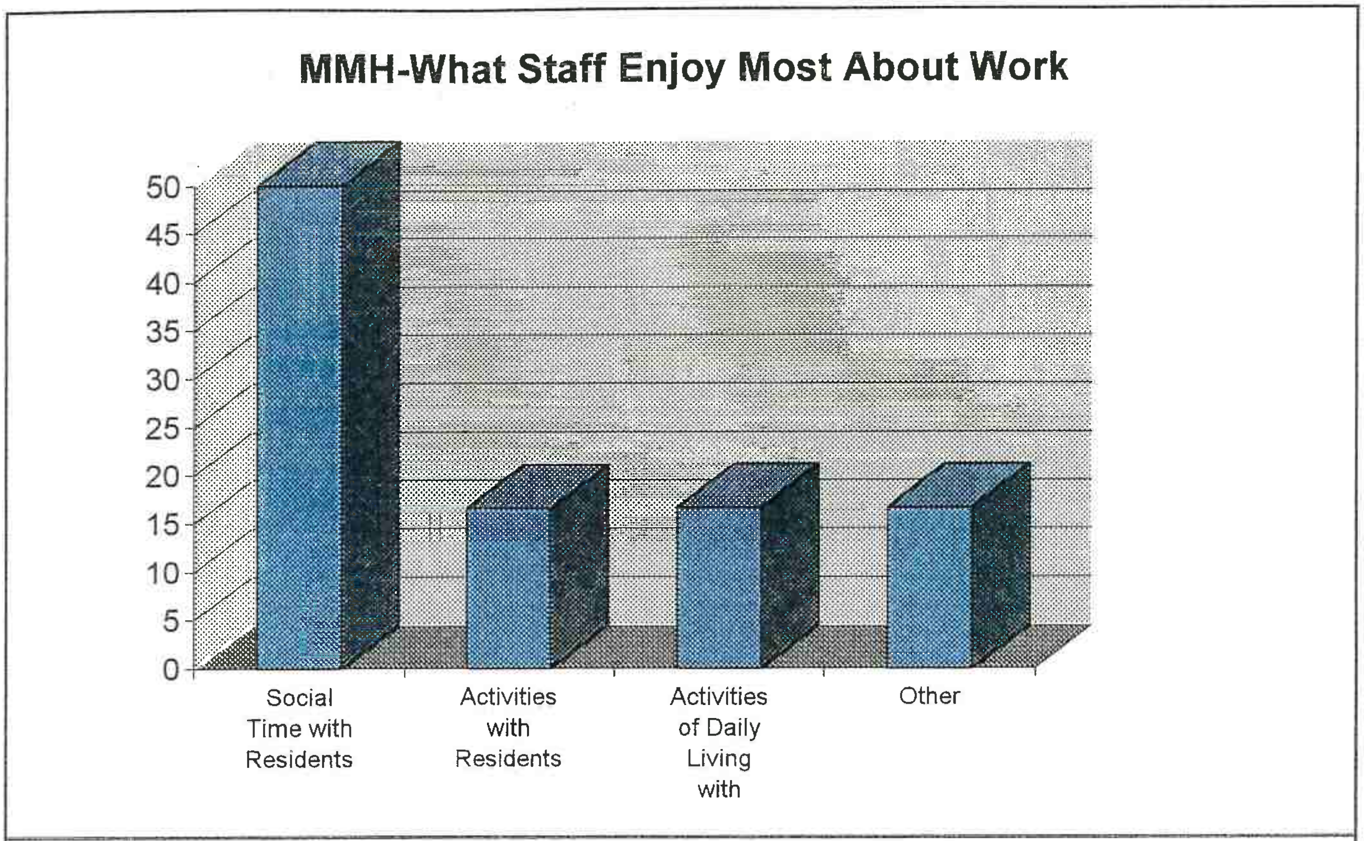


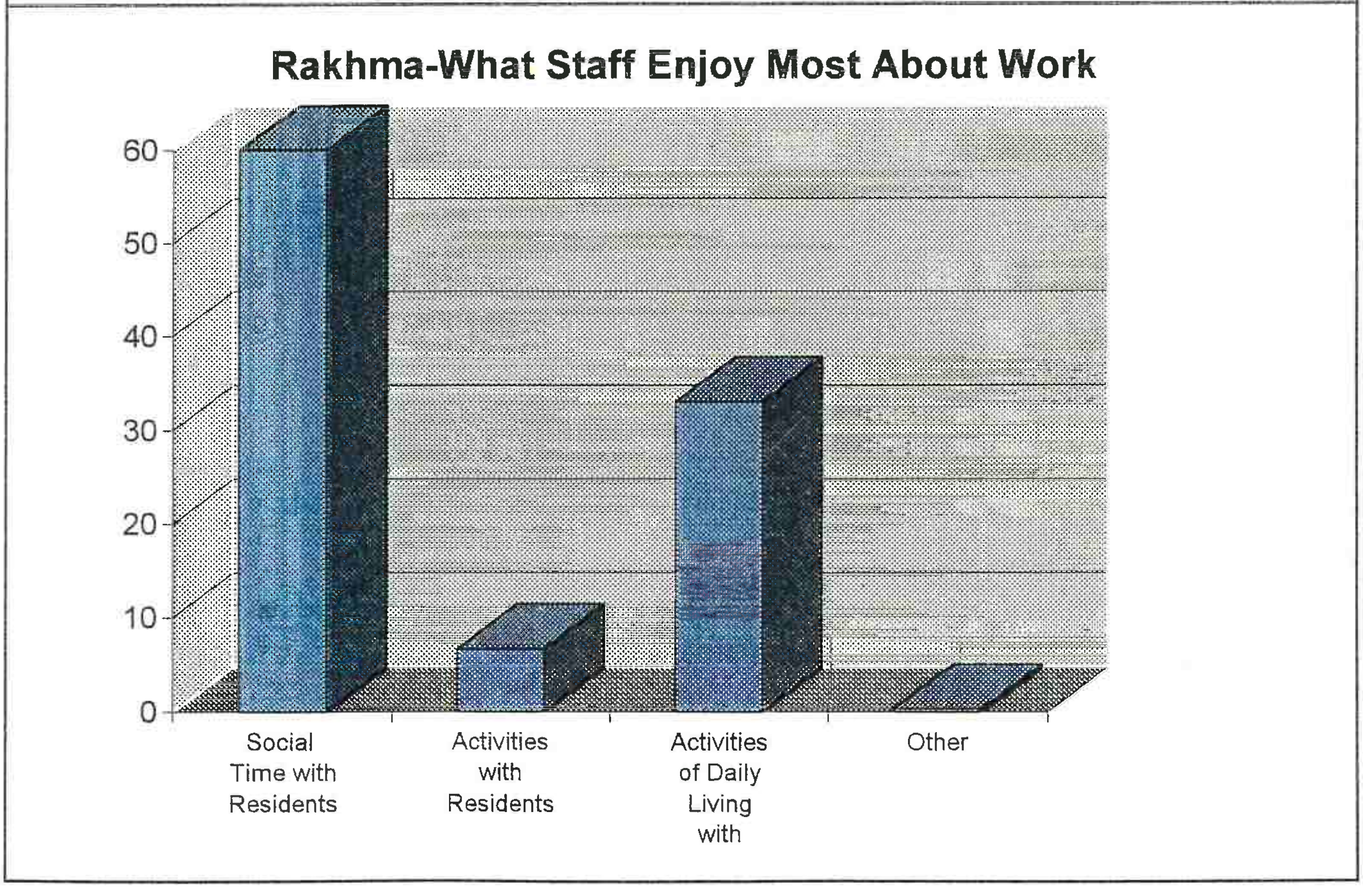
Mean 8.083
St. Dev 1.8



Mean 9.1
St.Dev 0.897

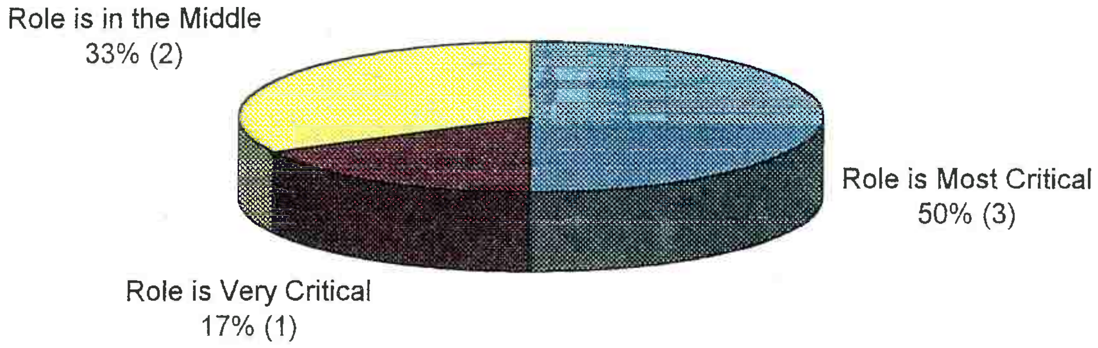
Attachment B



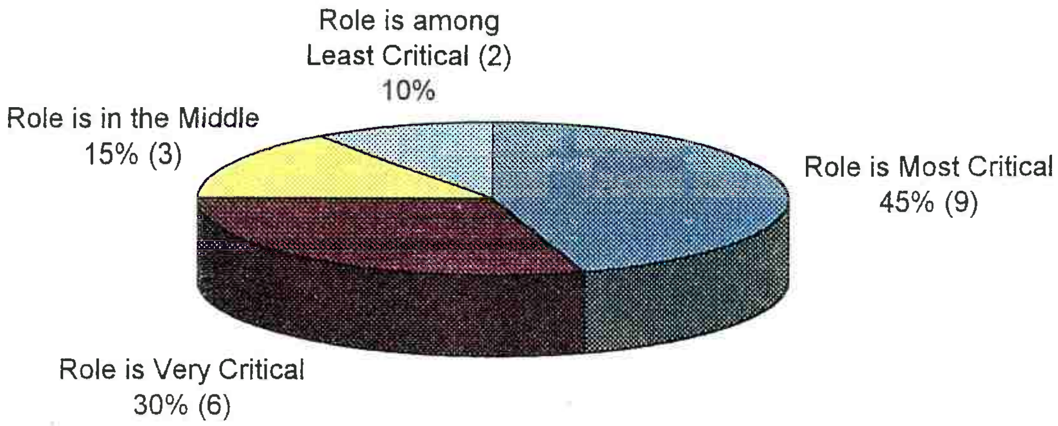


Attachment C

MMH-Importance of NA/R's in Ensuring Autonomy



Rakhma-Importance of NA/R's in Ensuring Autonomy



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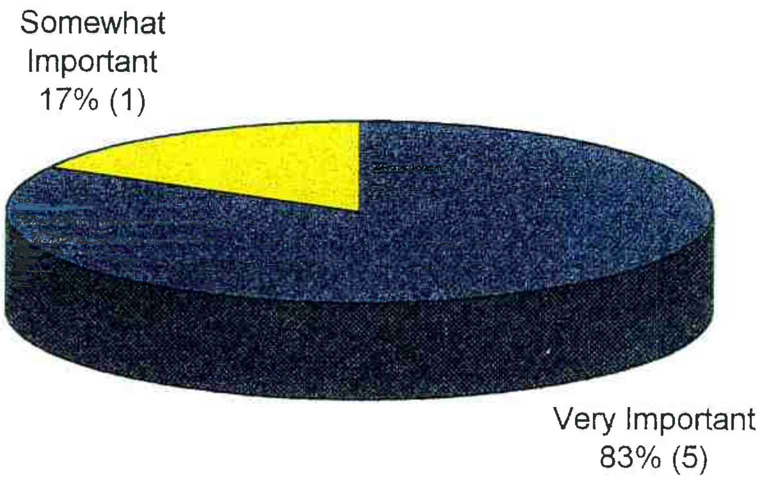
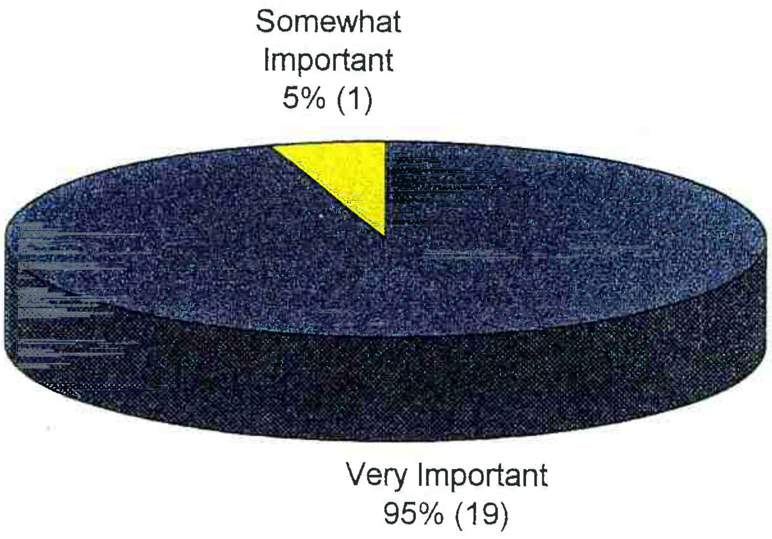
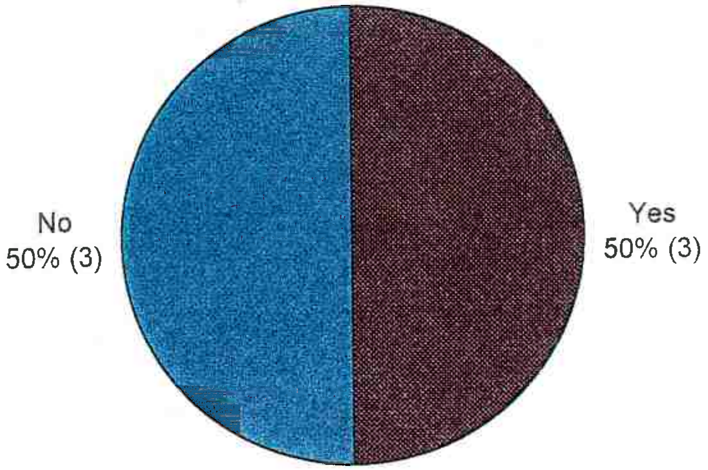


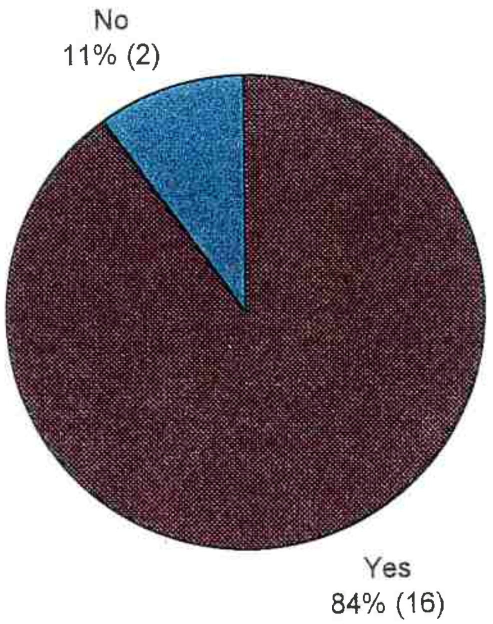
MMH-Importance of Preserving Autonomy



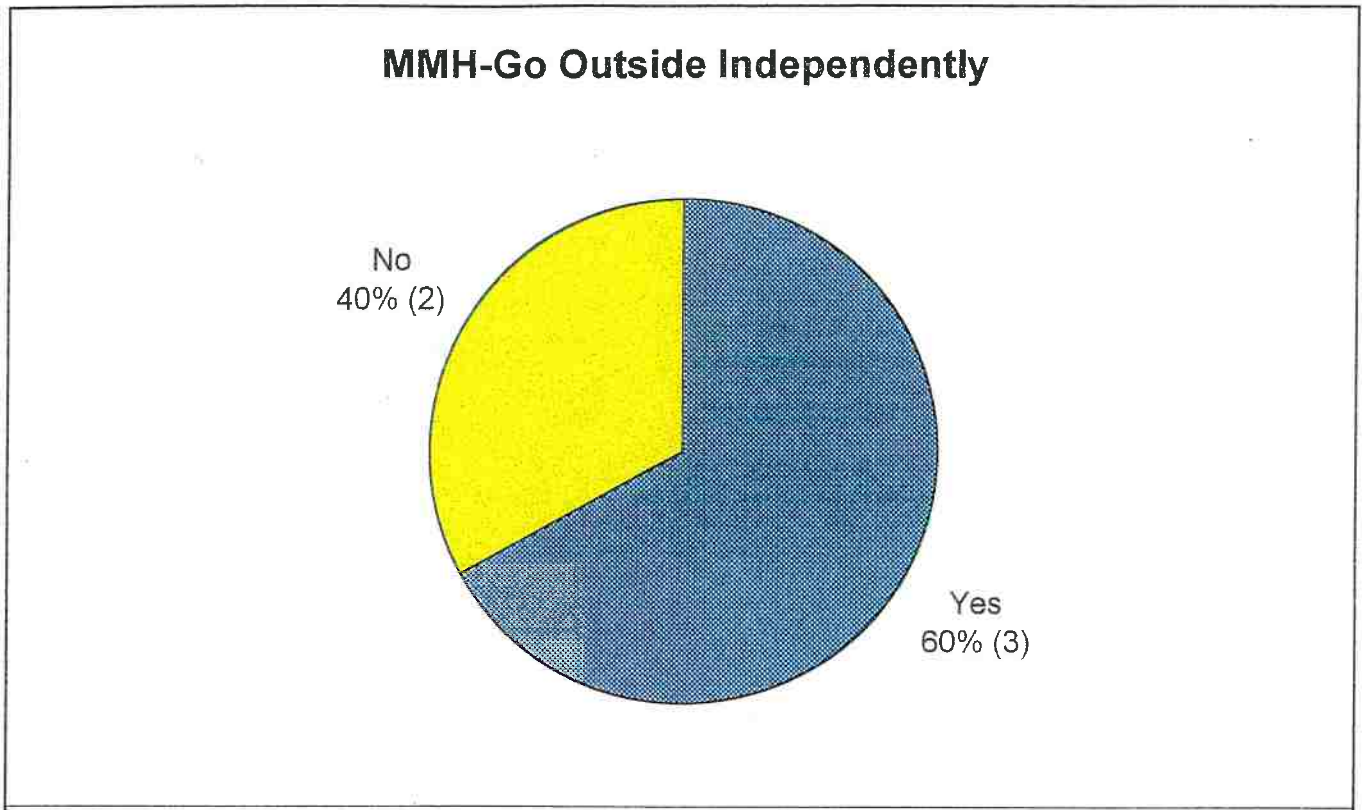
Rakhma-Importance of Preserving Autonomy

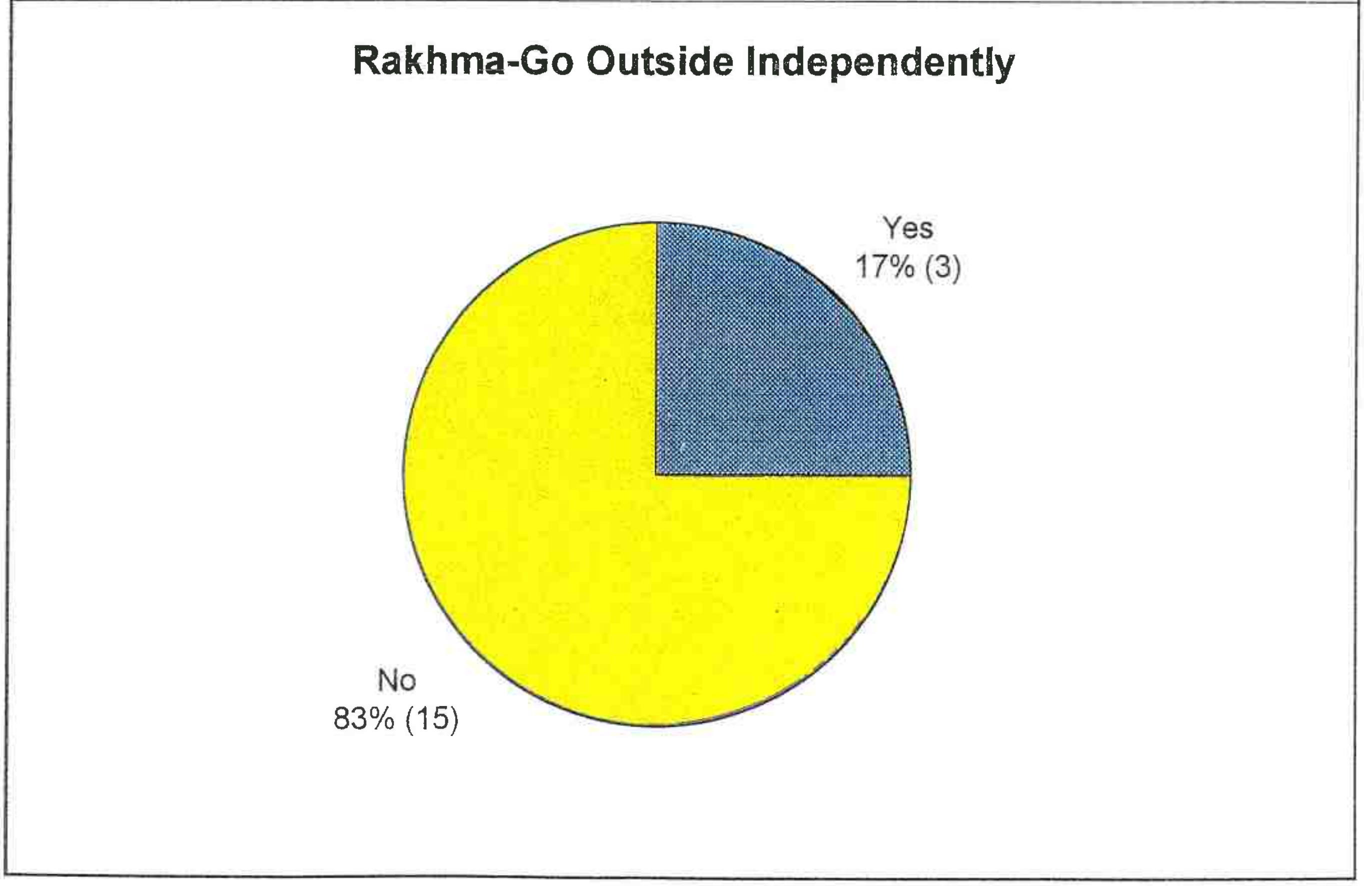
Attachment E


MMH-Choose Activities


Rakhma-Choose Activities

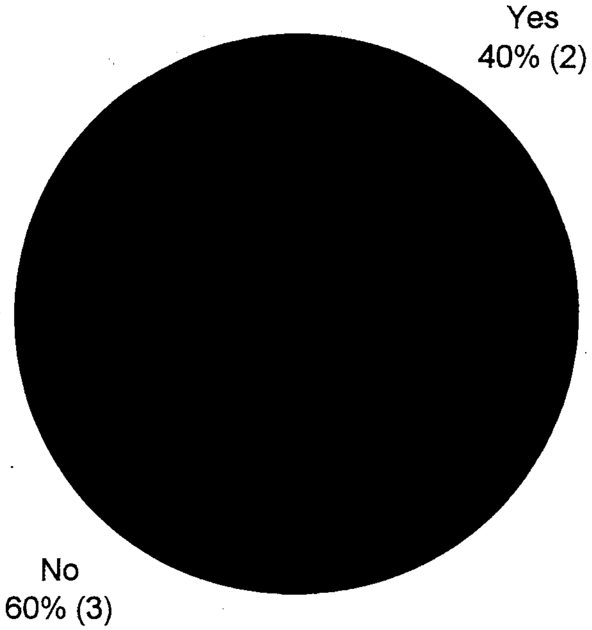
Attachment F


MMH-Go Outside Independently

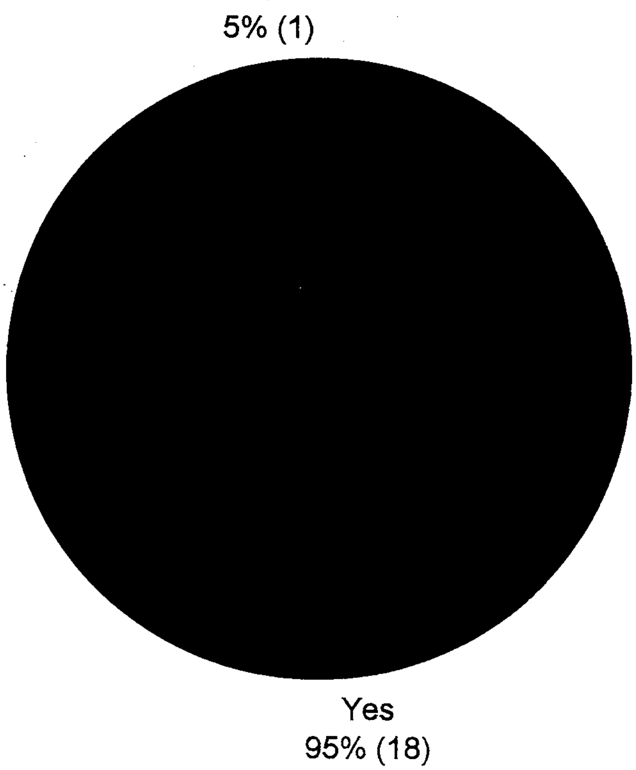

Rakhma-Go Outside Independently

Attachment G

MMH-Participation in Chores

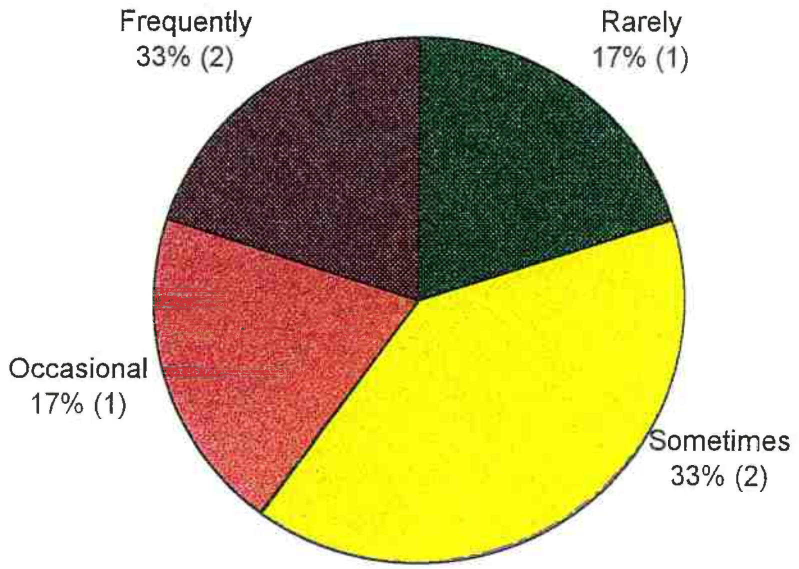


Rakhma-Participation in Chores

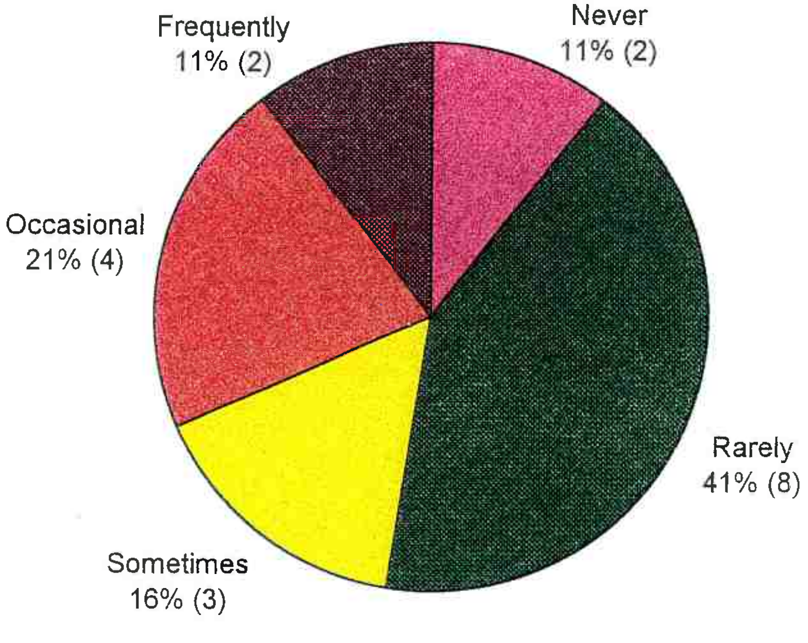


Attachment H

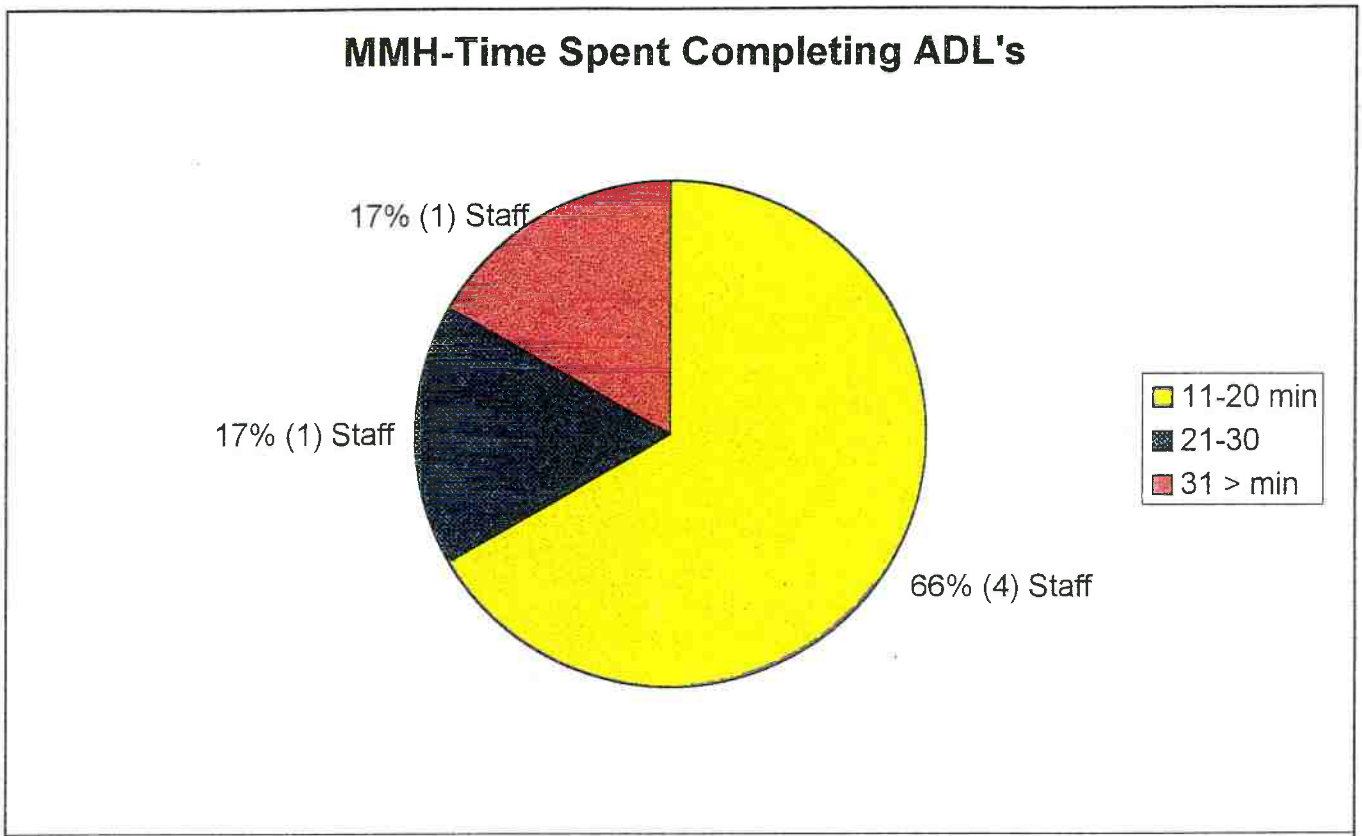
MMH-Utilization of Restraints

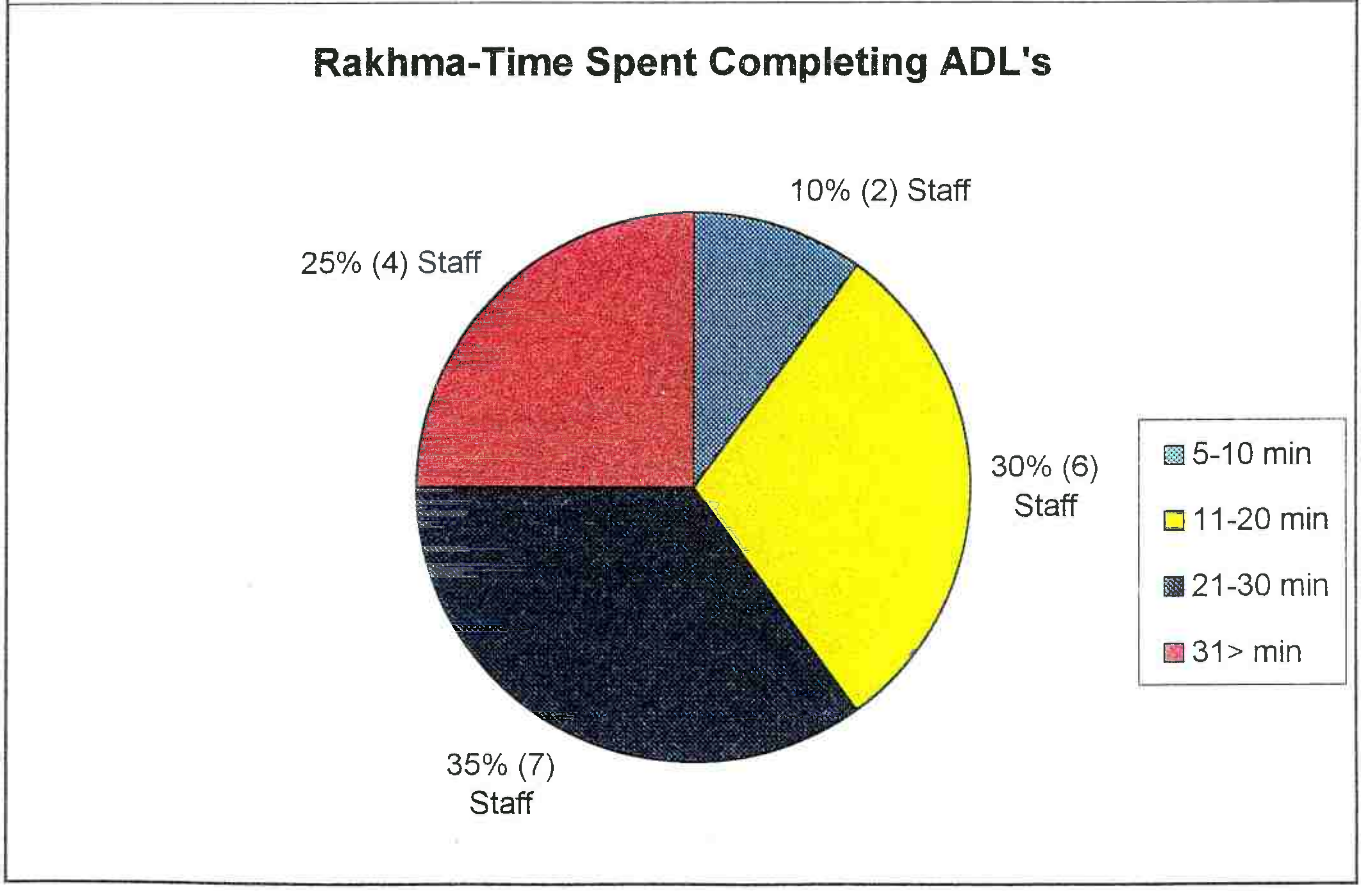


Rakhma-Utilization of Restraints

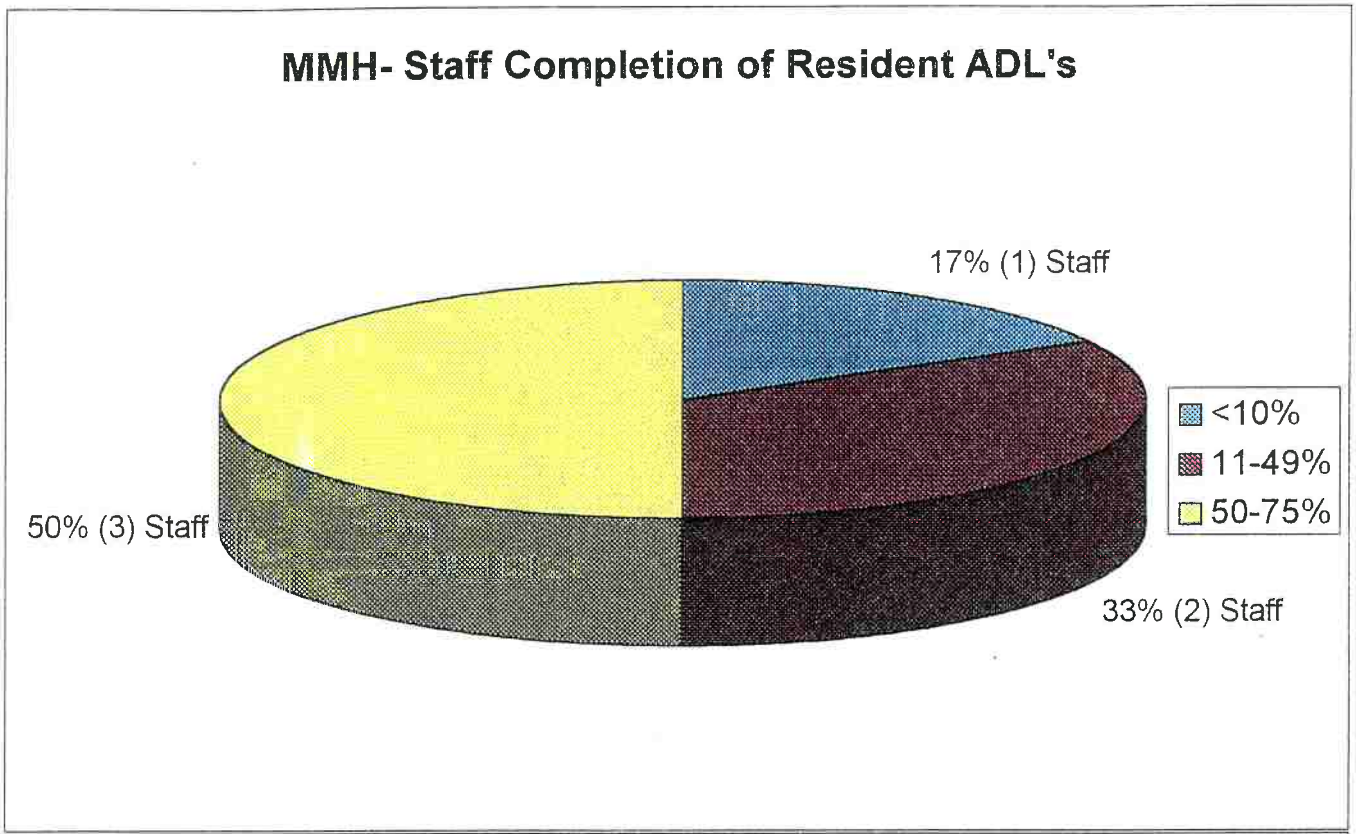


Attachment I

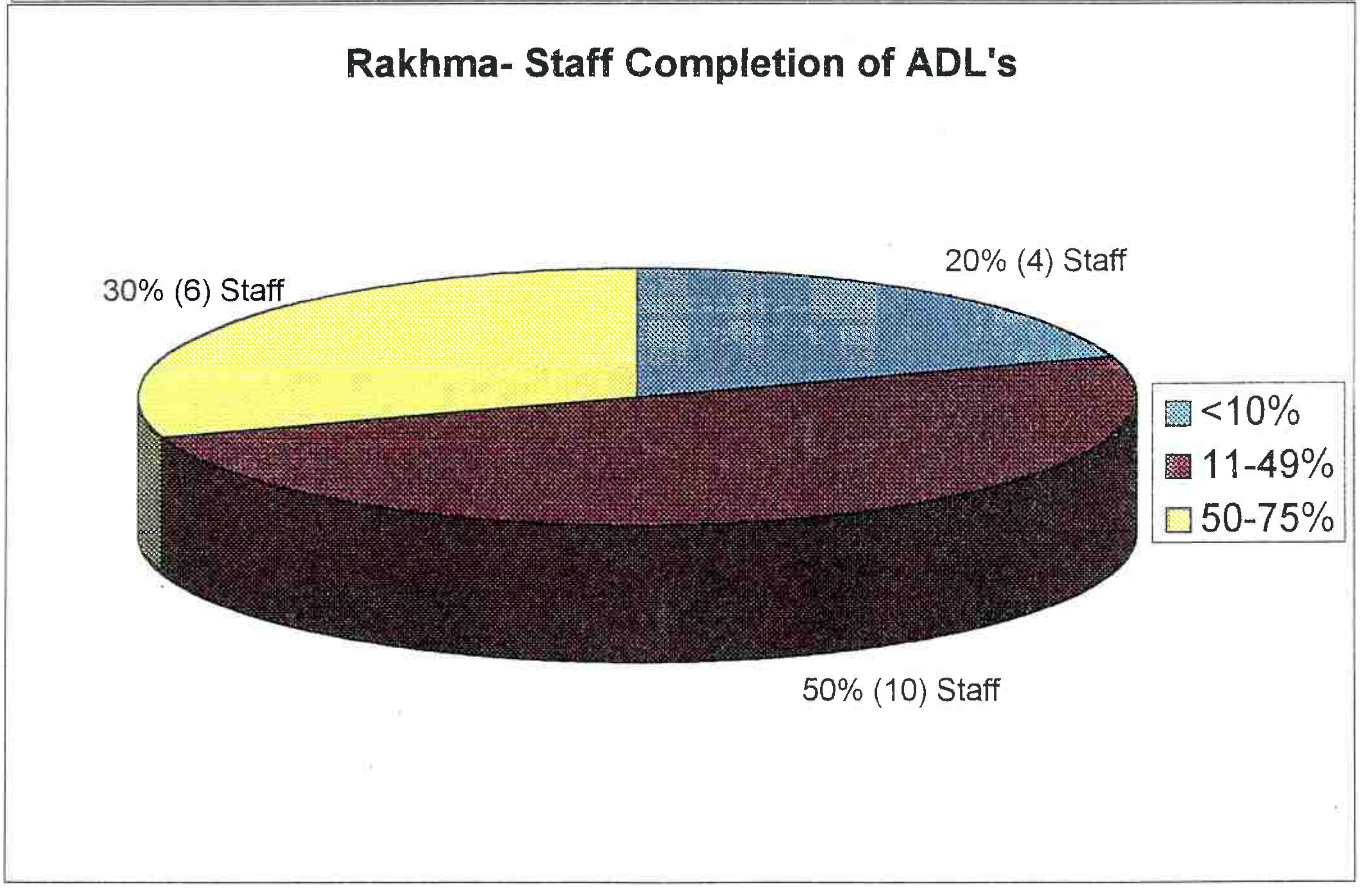




Attachment J

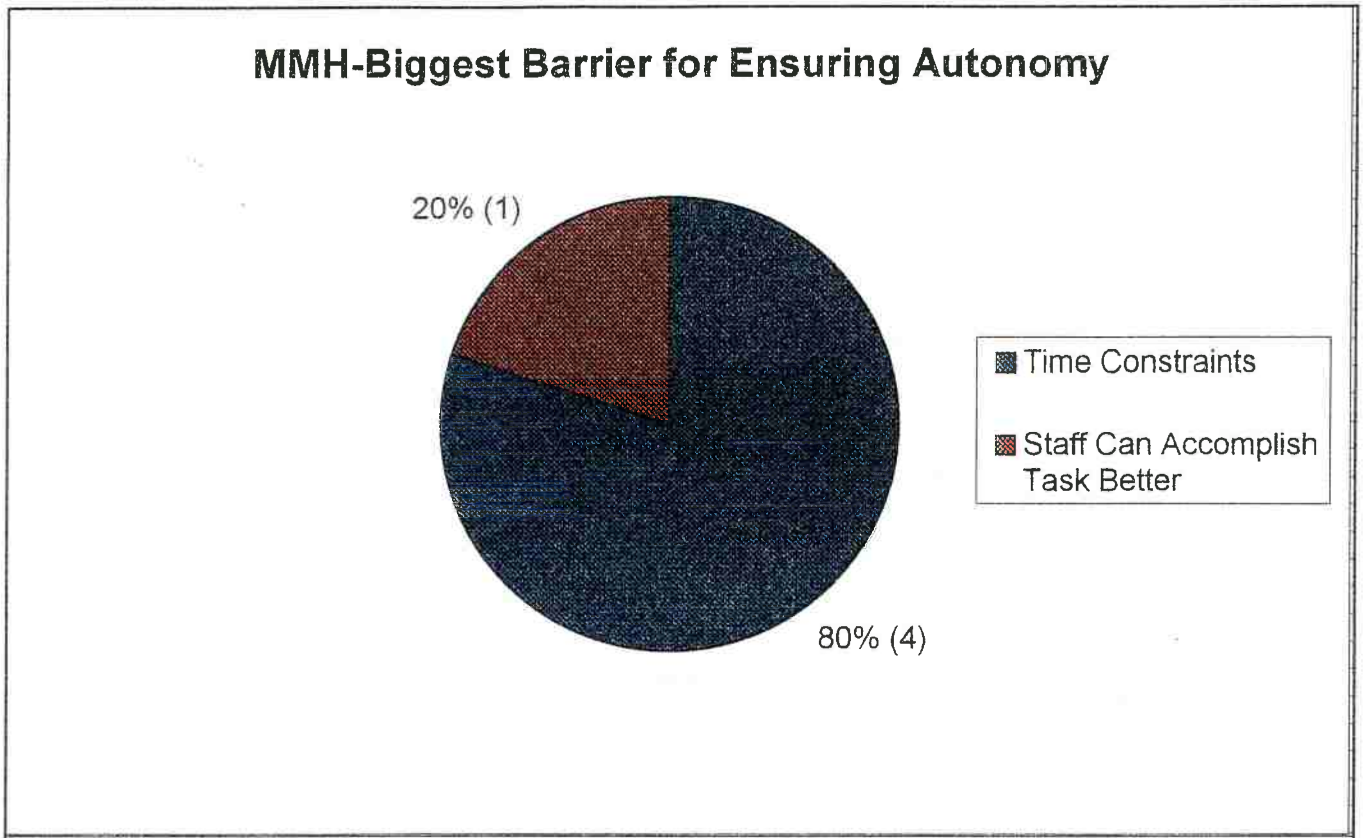


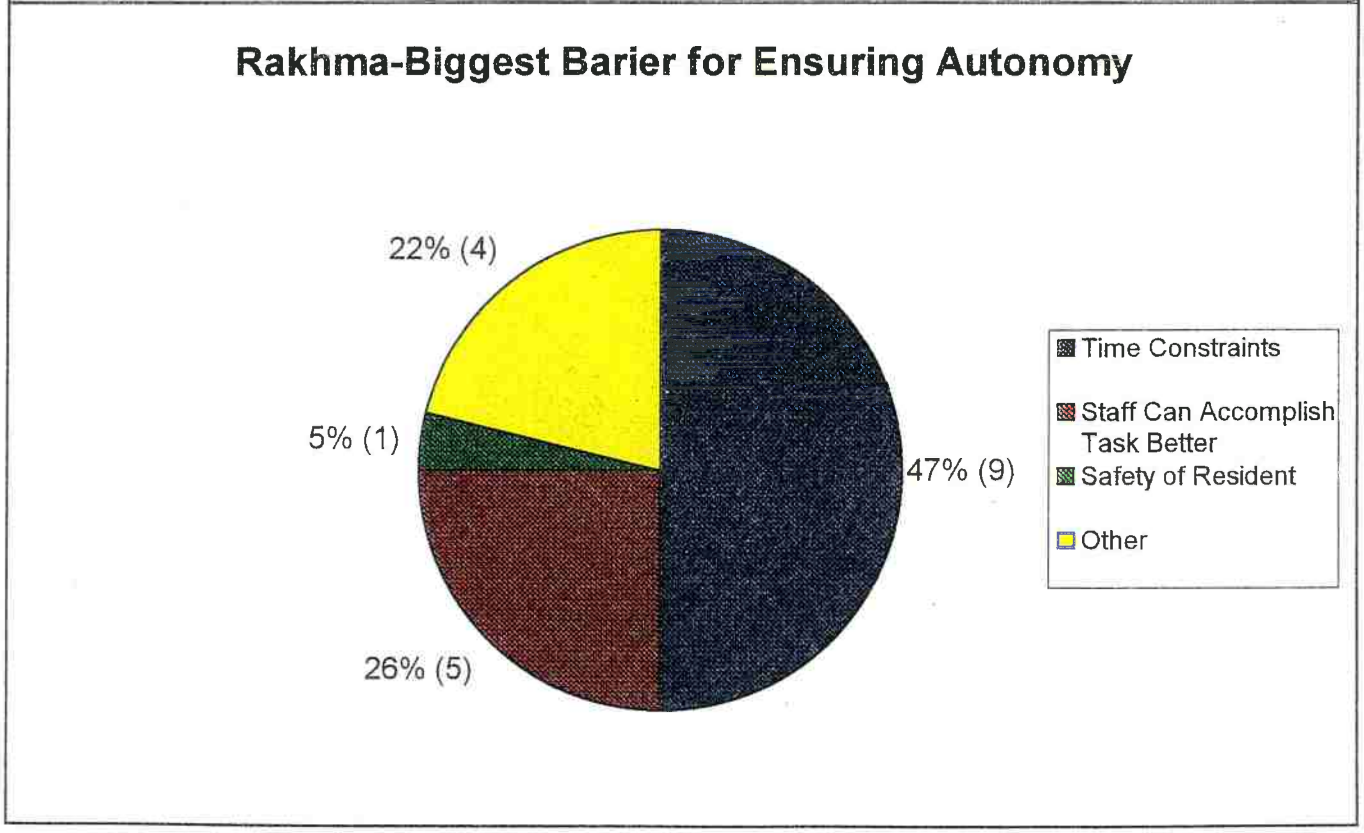
MMH- Staff Completion of Resident ADL's



Rakhma- Staff Completion of ADL's

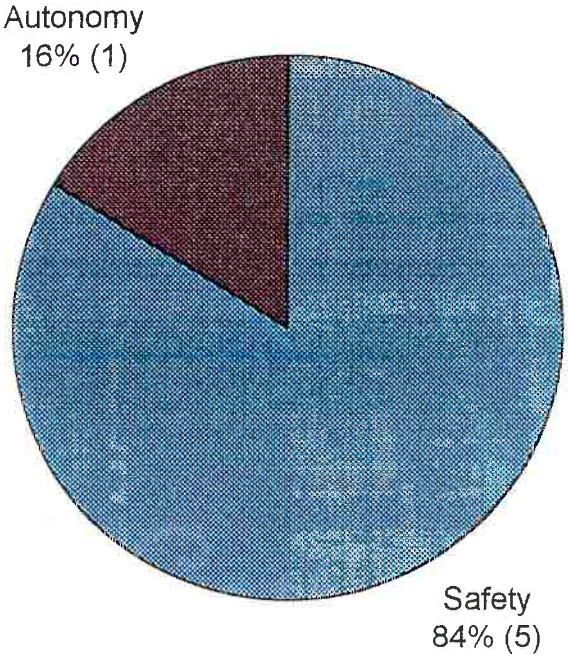
Attachment K


MMH-Biggest Barrier for Ensuring Autonomy

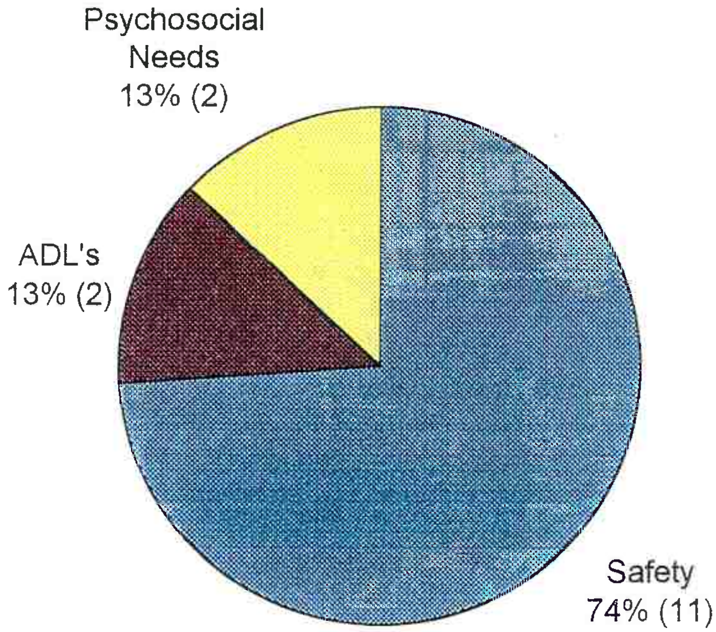

Rakhma-Biggest Barier for Ensuring Autonomy

Attachment L

MMH-Staff Perception of Importance

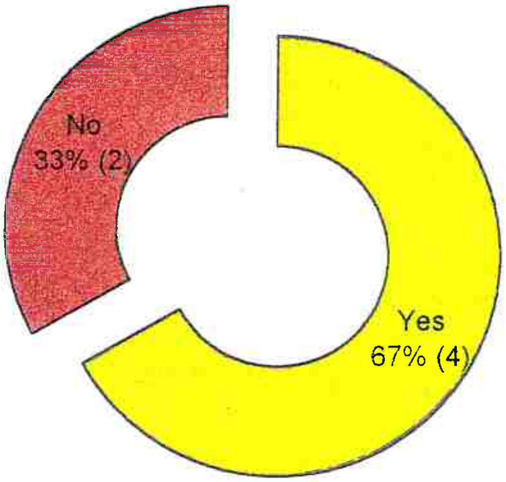


Rakhma-Staff Perception of Importance

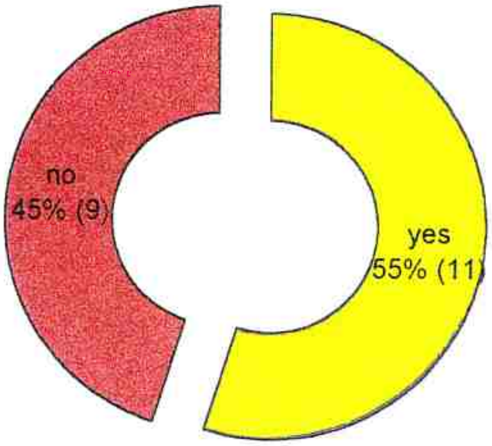


Attachment M

MMH-Is Facilty a Low-Stimulus Environment?



Rakhma-Is Home A Low-Stimulus Environment?



V. DISCUSSION

This chapter summarizes the significant findings of the study which are relevant to the literature review, the strengths and limitations of the study, implications of the study for practice and policy, and recommendations for further research.

Significant Findings and Major Trends Concurrent with the Literature

Both facility respondents reported high job satisfaction, which correlates with investment in resident well-being. If staff are happy with their jobs, the likelihood increases for staff to value resident autonomy. Staff from both facilities reported the most enjoyable part of their job is the social time they spend with residents; however, more respondents at Rakhma reported enjoying doing ADL's than staff at Masonic home did. The majority of both staff see their role as most critical of all elements in facilitating autonomy for the residents they care for. In addition, the majority of respondents at both facilities report that preserving resident autonomy is very important to them. This is in direct opposition to what the literature states about autonomy becoming a "disvalue" for the staff.

The major theme that prevailed from both facility staff about why it is important to preserve autonomy was that it enhances quality of life for the residents. However, across both facilities safety took precedence over autonomy, which is analogous with what is reported in the literature. It is interesting to note that at both facilities, staff reported time constraints hindering their ability to provide autonomy more than any other variable. Surprisingly, time restraints are the largest factor in preventing autonomy even in a smaller setting such as Rakhma. MMH and Rakhma staff both reported the need for more staff and volunteers on hand to facilitate resident autonomy. Staff to resident ratios must be lowered at both facilities. At Rakhma, paternalism was more of a theme preventing autonomy than at Masonic Home. Paternalism restricts autonomy and the notion of self-determination. MMH and Rakhma respondents both reported on the need for more staff and volunteers on hand to facilitate and ensure resident autonomy.

The majority of respondents at Masonic home reported spending 11-20 minutes completing ADL's per resident. At Rakhma, the majority of respondents said that they spend 21-30 minutes with residents completing ADL's per shift. Again, the more time spent with (higher functioning) residents, the more autonomy they are probably being given. This is because it takes more time to allow residents to complete ADL's for themselves as they are confused and often times forget how to tie their shoe or brush their teeth. However, 2 staff at Rakhma homes reported spending only 5-10 minutes with residents during ADL completion. These staff are probably doing all that can be done for the resident in order to complete cares quickly.

Both facility staff are responsible for approximately the same number of residents, 1-10. However, this should be taken with a bit of caution as Rakhma staff only ever have 10 residents in aggregate to care for. Masonic Home staff may have 10 residents each to be responsible for. The majority of respondents at MMH reported spending 50-75% of the time completing ADL's for the residents, instead of allowing them to complete the activities themselves. At Rakhma, on average respondents spent 11-49% of their time completing resident ADL's, instead of allowing residents to complete the activities themselves. Again, time constraints are what usually force staff to complete ADL's for the residents they care for.

Differences arose in the daily living opportunities for choice. At MMH, more respondents reported that residents could get up and go to bed when they wanted than at Rakhma. However, more respondents at Rakhma reported that residents could choose what they wanted to eat more readily than at Masonic Home. More respondents from MMH than from Rakhma reported residents could refuse to eat entirely. According to the respondents, more residents at Rakhma could refuse to bathe than residents living at Masonic home. More respondents at Rakhma than at MMH reported that residents could help choose activities. Masonic home respondents reported that most residents could not participate in the chores of the facility. In contrast, Rakhma staff reported that the majority of residents do participate in chores of the home. As reported in the literature, responsibilities in the environmental setting are essential determinants of resident life satisfaction (Namazi & Johnson, 1992).

From the results of the data, the trend seems to show that restraints are slightly more utilized at MMH than at Rakhma. This was consistent with what the literature reported, restraint popularity in nursing homes settings. It is essential to note, however, that restraints at MMH are used properly and not in excess. They are used only when there are no other options available. The most frequent description of resident restraint use at MMH was 'sometimes,' at Rakhma the most frequent description was 'rarely'. However, more residents at MMH are allowed to go outside freely with unlocked doors and more accessibility. Again, the literature reported that having the choice of going outside and not feeling locked up is important to the residents.

More MMH staff reported their homes as being a low-stimulus environment than staff did at Rakhma. From the respondents, the researcher is more likely to conclude that that residents at MMH experience less stress and therefore aberrant behaviors are curtailed due to a lowered PLST than at Rakhma homes. The Masonic Homes were reported to be less noisy and crowded than Rakhma homes.

Overall, the researcher concluded that the residents at each respective facility seem to enjoy autonomy in different areas, but that overall the level achieved is fairly consistent between the two. Both homes restrict autonomy as well, but it seems to be overshadowed by the enforcement of safety.

Strengths and Limitations of Study

A strength of this study lies in the benefit of participant anonymity. Because of the sensitive nature of the topic, if staff had been involved in an interview or if the data would have been gathered in a confidential manner, systematic error could have been more of a problem. Would staff really have admitted the truth and risked looking at the least ambivalent, if not uncaring, to the researcher? Another strength of the study is the high overall response rate, and the mixture of qualitative and quantitative questions and resulting responses.

A major limitation to the study is the small response rate from Minnesota Masonic Home. Can accurate comparisons really be made between the two facilities? This really limits the researcher's ability to draw valid comparisons between the two. Another limitation is that of internal validity. Are the responses from the staff indeed accurate and truthful? In addition, generalizations to similar facilities cannot be made. There is much ambiguity in the literature in defining the efficacy of Special Care Units. Therefore, if the effects of the SCU are unclear, how can the effects of an innovative structure such as the residential home be definable? Another limitation to the research was that the data collection instrument was in parts, unclear. For example, the researcher did not specify when asking about how many residents the staff care for. All respondents answered 1-10, even though a Masonic Home respondent could individually be responsible for 10 residents. Yet another limitation is researcher bias. Were the questions non-biased and the responses the researcher elicited truly representative of what was being said? The researcher has attempted to distance herself from the notion that a better quality of life is more attainable at Rakhma than at MMH. The data have shown that ideal *not* to be true. Not as many differences in resident autonomy between the two facilities showed to be true as the researcher had hypothesized.

Implications for Practice, Policy and Research

If nursing home personnel could demonstrate that they provide autonomy for residents, would the fear of nursing home living abate? Social workers are instrumental in the advocacy of autonomy for residents with dementia who inhabit long-term care facilities, whose voices often fall silent in the institutional setting. Practicing social workers and health care providers need to be attuned to this often overlooked and diminished aspect of resident quality of life. Social workers need to work with the nursing assistants in the facilities, where often times each discipline doesn't have much interaction with one another, even though everyone is working collaboratively to ensure resident well-being. My personal belief in how essential it is for residents to experience autonomy has only been strengthened by this study. I will continue to advocate for, and work with the nursing assistant staff, to provide as much autonomy as possible for the residents at Rakhma.

Autonomy can be improved in the long-term care setting by investing in good, solid staff who are happy with their jobs and are committed to providing dignity for the residents they care for. One way to do this is to advocate for more funds through the legislator to pay higher wages for nursing assistant staff, as they currently receive on average eight dollars an hour for the critical job they occupy. Another way for social workers to advocate for resident autonomy is to lower staff to resident ratios. However, money is the bottom line. If more staff are needed, more scarce funds are needed to pay for the increase in staffing costs.

Invariably, autonomy is analogous with self-determination. As stated in the introductory chapter, neglect of this core value can result in a paternalistic attitude and approach to clients (Wesley, 1996). Autonomy is a determinant of dignity and quality of life and it is a responsibility all of us share.

If further studies were to be conducted and it was shown that resident autonomy and quality of life were better achieved in a residential setting, policy would need to be in place to service indigent elderly. Because residential care homes are not regulated by the government, they are also not privy to government funds and are usually private pay. This payment structure precludes many people from the opportunity to live in a residential home setting, and often narrows their "choice" of facilities to a nursing home Medicare wing.

Future research could expand this study to include a larger sample population and an opportunity to directly investigate resident wishes for increasing personal autonomy. What do residents with memory loss wish for to live their lives as autonomously as possible? With the ever-expanding elderly population, the issue of autonomy will continue to be a central determinant of "successful aging."

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Appendix A

Survey for Direct Line Staff: Nursing Assistant's

Demographics of Staff

1) How long have you been a NA/R? _______ years ________ months

2) What are your qualifications related to your job? (for example, are you certified by the State?)______________________________________
____

3) What facility do you work in, please circle one and indicate which wing or home:
A. Minnesota Masonic Home Unit: North, West, South
B. Rakhma Home: Peace, Grace, Joy

4) How long have you worked in this facility?_________ years ________ months

5) On a scale of one to ten, please circle how much you enjoy your job.

1	2	3	4	5	6	7	8	9	10
Completely Dissatisfied				Neither Satisfied Nor Disatisfied					Completely Satisfied

6) What do you enjoy most about your work? Please list one through five, one being what you enjoy most, and five being what you least enjoy.

______Social time spent with residents
______Doing activities
______Assisting residents complete Activities of Daily Living (eg. dressing, bathing, eating)
______Interacting with other staff
______Other (please explain)______________________________________
____

Staff Perception of Resident Autonomy

Autonomy, for these purposes, is defined as choice and independence.

Activities of daily living(ADL's) are defined as helping the residents to do such things as eating, dressing, oral care, bathing, etc.

1) Please circle Y for yes, N for no.

Can residents in your facility get up when they want to?	**Y**	**N**
Can they go to bed when they want to?	**Y**	**N**
Can they chose what to eat?	**Y**	**N**
Can they refuse to eat entirely?	**Y**	**N**
Can they refuse to bathe?	**Y**	**N**
Can they help choose activities?	**Y**	**N**
Can they participate in the chores of the home or facility?	**Y**	**N**
Can they close their doors?	**Y**	**N**
Can they refuse visitors?	**Y**	**N**
Can they go outside freely, without your help?	**Y**	**N**
Are they ever restrained?	**Y**	**N**

Please elaborate on any of the above questions in question number 1 ***if you'd like:***

____
____
____
____
____
____
____

2) How often does your facility utilize restraints (including medications) to contain difficult behavior, if needed? Please approximate.

A. Never
B. Rarely
C. Sometimes
D. Occasionally
E. Frequently

3) What condition(s) warrant restraints?

____
____
____
____

4) Who decides if the residents are restrained? Circle all that apply.

A. The RN
B. DR's order
B. You
C. Written order from family
D. The administrator or manager of facility

5) How do you, as a caregiver, balance the resident's freedom with their safety?

____
____
____
____

6) a) How much time, on average, do you spend with each resident when completing activities of daily living? Please circle closest approximation.

A. 5-10 minutes
B. 11-20 minutes
C. 21-30 minutes
D. 31 minutes or more
E. Other

b) For the above answer, what takes the most time in assisting residents?

____

7) Please circle how many residents you provide direct care for, per shift, on a given day.

A. 1-10
B. 11-20
C. 21-30
D. 30 or more
E. Other

8) Due to time limitations, what percentage of the time do you, as staff, complete activities of daily living for residents, versus allowing them to complete activities themselves?

A. Less than 10% of the time
B. 11-49% of the time
C. 50-75% of the time

D. Over 76% of the time

9) What would you recommend to increase residents' opportunity for choice?

____

____

____

____

10) What do you see as the biggest barrier you face for ensuring resident's choice and freedom? Circle one.

A) Time constraints, having too much to do
B) Feeling you can accomplish task better than the resident
C) As the caregiver, having little patience
D) Not caring about resident decision making
E) Feeling burned out
F) Lack of support from facility
G) Other (please explain)______________________________

____

11) Do you find differences in autonomy among different levels of affliction with Alzheimer's disease? That is, are people who are further advanced with the disease less likely to experience opportunities to choose?
Yes______ No______

Comment on above answer______________________________

____

____

12) Please choose one of the following that best explains how critical ***your role*** is in preserving choice and independence for the residents living here:

1) My role is the most critical of all elements shaping autonomy in the residents' life
2) My role is very critical
3) My role is in the middle
4) My role is among the least critical
5) The least critical

13) Please circle what level of importance preserving residents' autonomy has for you:

A. Very important
B. Somewhat important
C. Not important at all

b) Why is it important or not important for you to preserve residents' autonomy?

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14) Please rank the following four goals in order of importance to you (1=most important and 4= least important)

______Ensuring activities of daily living are met
______Safety
______Meeting psychosocial needs (including activities, affection, recreation, conversation, comfort, time spent one on one, spiritual needs)
______Autonomy

15) How important would you say the physical environment, the design of the facility you work in, is on hindering or encouraging resident choice and self-direction? Please circle one.

A. Very important in allowing or restricting choices
B. Is somewhat important
C. Has no effect on allowing or restricting choices

16) How would you rate the overall quality of life of the residents' you care for? Please circle one:

1	2	3	4	5
Poor				Excellent

17) Would you say that your facility or home provides a low-stimulus environment for your residents? (eg. it is not overly busy, too loud, too crowded etc.)

A. Yes B. No