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The effects of nursing home placement on the stress levels of caregivers

Ellen E. Thomson

Rowan College of New Jersey

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THE EFFECTS OF NURSING HOME PLACEMENT ON THE STRESS LEVELS
OF CAREGIVERS

BY
ELLEN E. THOMSON

A THESIS

Submitted in partial fulfillment of the requirements of the Masters of Arts Degree in the
Graduate Division of Rowan College
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Approved by _____

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ABSTRACT

Ellen E. Thomson The Effects of Nursing Home Placement on the Stress Levels of Caregivers 1995. Thesis Advisor: Dr. John Klanderman. School Psychology Program.

The purpose of this study was to discuss the relationship between nursing home placement and anxiety levels of the people placing their loved ones. The study used 20 subjects from a nursing home in southern New Jersey. Subjects were people who had cared for a parent at home for at least one year prior to placement. Subjects were administered the IPAT anxiety scale on the day of placement and again one month later.

Relationships were shown through T-Tests and correlation coefficients. This study indicated that there were significant changes in anxiety levels of subjects after a one month period.

MINI ABSTRACT

Ellen E. Thomson The Effects of Nursing Home Placement on the Stress Levels of Caregivers 1995. Thesis Advisor: Dr. John Klanderma. School Psychology Program.

The relationship between nursing home placement and stress levels of caregivers was investigated. The study showed that there were significant differences in stress levels at the time of placement and one month after placement.

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CHAPTER 1

PROBLEMS AND ITS SCOPE INTRODUCTION

Today medical technology has greatly increased the life span of humans. As a result we have the young old (65 - 75) who are strong and healthy and we have the old (76 - on up) who live longer with chronic disease. Approximately 86 percent of older adults experience at least one chronic illness (Office of Technology, 1985). The proportion of elderly people in relation to the population in the United States has risen significantly. Just since 1900 to 1985 the total population has gone from 4 percent to 12 percent for people over the age of 65. That is an increase of 25 million in 85 years (Stephens, 1990).

This phenomena has created an increased need for supervision and assistance. Nearly one-fifth of older adults require partial assistance with Adult Daily Living Skills (ADLS) (Gilford, 1985). This really began to show its face in the early 1960's. Medicaid did not come into existence until 1965. Prior to this the responsibility was placed on the adult children who by this time may be over 65 themselves. Long term facilities did not come until the late 1970's (Brody, 1990). The only alternatives would be to hire an aid or take care of the elderly person yourself. Financially many people could only afford the latter.

The life styles within this time frame have changed. The standard housewife is an endangered species. Many of today's families require two incomes; therefore, we have a much higher rate of women in the work force, unable to stay at home and care for sick or cognitively impaired elderly. This presents the problem of what to do with the elderly loved one. Many children are guilt ridden because they have promised a dead parent that

they will take care of the survivor forever. They may feel that they have let their parents down by placing them into a nursing home. This guilt may lead to stress/anxiety over finding a nursing home, being placed on a wait list or anxiety over worrying about the care their loved one is receiving once placed. The big question that creates that most conflict is "Am I doing the right thing?" This question is often never answered, but it can not be answered until after placement and an adjustment period.

PURPOSE

It has been noted that by the year 2030, one out of every five people in the United States will be over the age of 65 (Brody, 1990). That is over 64 million, representing 21 percent of the total population. More and more people will be faced with the fears and stress of placing their loved ones in a nursing home. Stress can cause a wide range of physical problems. Recent studies have shown that "stress raises blood pressure, squeezes the heart's coronary arteries and causes them to go into spasms and it may also increase chemicals in the blood that can create clots" (US News and World Report, 1990). If the stressful situation persists it can cause weakened arteries and heart tissue. People who have already had one heart attack have a two to three times greater chance of being killed by excess stress (US News and World Report, 1990). Researchers have also found that people who have arteriosclerosis are more at risk when placed in stressful situations. When placed in such a situation, the adrenal gland puts out epinephrine. People with this disease not only have excess plaque clogged vessels, but also have an inferior vascular ability to handle stress. Normal blood vessels react to the epinephrine by creating Endothelium Derived Relaxing Factor (EDRF). People who are not healthy to begin with when placed under stress are unable to properly produce EDRF, thus they have a higher chance of a heart attack (Fackelmann, 1991).

This study is looking at the stress levels of caregivers admitting their loved ones into a nursing home. It will track stress/anxiety levels in an attempt to understand the feelings of the caregiver. If the emotions and feelings of the caregivers can be better understood, the social workers in the facility can be better trained to work with them. This study will lend support to the need for all nursing homes to have a support group available for all family members. It will also increase the need for agencies like CAPS (Children of Aging Parents).

HYPOTHESIS

Stress/Anxiety levels of people admitting their loved one into a nursing home will decrease in a one month period, in comparison to the time of admission.

ASSUMPTIONS

1. It is assumed that: The subjects will honestly and objectively answer the stress/anxiety questionnaire.
2. It is assumed that: The Institute for Personality and Ability Testing Anxiety Scale is a highly valid and reliable measure.
3. It is assumed that: The populations will be of similar ages. They will be between the ages of 65 and 70, therefore will most likely be retire and have similar stress levels outside those generated by nursing home placement.
4. It is assumed that: The family member will have previously cared for their loved one in their home for at least one year. Family members will have had to deal with the stress of actually taking care of the elderly person and will have that stress of finding the proper home and actually dealing with the placement.

LIMITATIONS

1. The population was gathered over a three to four month time frame, therefore, this is not a representative sample of the entire nursing home population.
2. Differences in socioeconomic status, may result in differing levels of stress.
3. Because of time constraints, period of time between pre and post test may not be sufficient.

DEFINITIONS

Medicaid: Government funding that provides payment for hospital and medical services to people who cannot afford them. Funding comes from federal and state governments under the auspices of the U.S. Health Care Financing Administration.

Long term care/skilled nursing care: Offers maximum nursing care to residents who require twenty-four hour licensed nursing supervision. Full time skilled nursing home care is provided in nursing homes. Only these facilities offer comprehensive, long-term nursing care, maximum assistance with daily living tasks, and medical practices and procedures for life support. Skilled nursing care is a step below the level of care provided in an acute-care hospital (Greenberg, 1989).

Stress/Anxiety: Feelings of uneasiness or tension that interferes with the normal functioning of a person or produces some type of internal strain.

ADLS: Adult daily living skills. These consist of washing and dressing one's self. Being able to go to the bathroom by alone as well as being able to feed one's self.

Wait List: A list an elderly person who is interested in a nursing home is placed on when there is no room. When a space becomes available, the family will be notified.

Arteriosclerosis: Hardening of the arteries, a condition that makes it difficult for the blood to circulate.

Adrenal Gland: Endocrine glands located at the upper end of the kidneys.

Epinephrine: A hormone that increases heart rate and makes blood vessels smaller.

Endothelium Derived Relaxing Factor (EDRF): A nitroglycerin like substance.

OVERVIEW

In Chapter 2 a review of past literature on coping with caregiving will be presented. Chapter 3 will discuss the sample, measures and procedure of the study and Chapter 4 will discuss the actual research findings. Finally, Chapter 5 will discuss any implications from the experiment as well as discussing any possible ideas for future research. Nursing home placement is an issue that is being addressed by more and more people every year. To be faced with the decision of institutionalization of a mother or father can be very stressful. This study hopes to show that stress levels decrease once the burden of caregiving is taken away and adjustment to placement has occurred.

CHAPTER 2

People in today's society are living longer, placing them at higher risk for chronic illness or disease. Even though the topic of nursing home placement and the stress involved in placement is relatively new, the research being done that looks at the effects caring for someone has on a person is vast. Research ranges from the stress the caregiver is under to the quality of the caregiver's employment to stress causing caregiver to abuse the care receiver.

IN-HOME CARE VERSUS NURSING HOME PLACEMENT

In a study done by Stephens, Kinney and Ogrocki (1991), the differences between stressors and well being in caregivers who care for a loved one with dementia at home and those who had admitted their loved one into a nursing home were looked at. They had a sample size of 120 primary caregivers to elderly who have Alzheimer's disease. One half who cared for their family member at home and the other half whose loved one had been placed in a nursing home. For the second group to qualify, the caregivers had to have been the primary caregiver prior to nursing home placement; placement must have been within the last five years and they must visit at least once a week. The instruments were the Caregiving Hassles Scale used to assess stress and the Caregiving Social Impact Scale to determine the level of the caregiver's social, psychological and somatic well being.

The results reported that the most common hassle that created the most stress of caregivers from both groups was the care recipients cognitive limitations. Both groups identified the same problems as being hassles. This was an important finding, because care

recipients in nursing homes had more severe cognitive impairment than those at home, as well as those caregivers had less frequent contact with these problems than did the other group. When the two groups were compared on the overall hassles experienced, there was a difference between the two. When the number of problems was controlled, the second group reported higher levels of stress. It is thought that this may be due to the fact that nursing home caregivers have always found these problems stressful and that this stress pushed them into nursing home placement.

Both groups reported not receiving support from family and friends as a predictor of stress. The difference being the impact. For the nursing home caregivers, lack of support was thought to be due to restrictions in the caregiver's social activity. The in home caregivers on the other hand associated it with depression.

Even though caregivers who have placed their loved ones into a nursing home have less responsibilities for as well as contact with the care receivers; however, they tend to experience events in caregiving as more stressful than in comparison to those who care in home. The relief experience by those people who have their loved ones in a nursing home is based more in terms of their social lives than with their mental and physical health. From this study Stephens, Kinney and Ogrocki (1991) have found that even though nursing home placement may alleviate some stressors that were experienced when their loved one was at home, it by no means eliminates stress especially if the caregiver maintains contact after placement.

PRIMARY AND SECONDARY STRESSORS

Similarly Pearlin, Mullan, Semple and Skaff (1990) have a study that is still in progress which targets similar stressor from the prior study. They are currently looking at a sample of 555 caregivers from a general area. All primary caregivers have a spouse or parent that is not in a nursing home and has Alzheimer or a similar dementia. There will

be three interviews conducted over a two year period during which the change brought on by nursing home placement, death and household changes will be documented. Only the first interview has been documented. They have defined the causes of stress, breaking them into primary and secondary stressors.

Primary stressors have been broken down into two categories: objective and subjective indicators. The first objective indicator is cognitive status. This was found to be the cause of high levels of stress due to memory loss of the recipient, thus the inability to remember names and faces. The cognitive impairment may bring rise to one of the other objective stressors, problematic behavior. Problem behaviors force the caregiver to monitor and control the receiver. They have to deal with making sure the receiver does not hurt himself or others. This behavior acts as a constant reminder of change that has gone on. The next area that appears as a stressor is the need for assistance with ADLS. The more dependent the person is the more work that is involved. This study had found that it is not the amount of work performed, but rather the resistance that is met when trying to help. The other types of primary stressors are those that are experienced subjectively by the caregiver. One of those is the burnout the giver feels. Feelings of both physical and mental fatigue. The other is relational deprivation, the care receiver is often "no longer himself". He is unable to communicate his needs, changing the entire caregiver - recipient relationship.

The secondary stressors that Pearlin, Mullan, Semple and Skaff (1991) identify are the product of the primary stressors over a time period. The most important being the family. This study found that very often conflict between the caregiver and other family members may arise due to different opinions regarding care, the seriousness of the receiver's health or nursing home placement. Conflict was also found to arise between spouses when one was caring for a parent. The problem seemed to come from one feeling like the other had forgotten or did not care about them. No matter what the cause of the

conflict, it was found that discord within the family create the one of the greatest amounts of stress.

Employment and economic strains were also apparent. The study found that those people who are employed outside of the home "frequently experience cross-pressures and dilemmas at the junctures of caregiving and occupation" (Pearlin, Mullan, Semple and Skaff, 1990). Economic strains were determined to be caused by a reduction of household income, increase in expenses related to care and treatment as well as whether there are sufficient funds to pay the bills from month to month. They do not make any causal links because economic hardships may have existed prior to having to be a caregiver. This study notes that the stress a caregiver experiences is not a universal event. It is rather a mixture of circumstances, experiences, responses and resources (Pearlin, Mullan, Semple and Skaff, 1990) that are unique to each individual, as are the ways the stress is handled by the caregiver.

COMMON STRESSORS AND CAUSES OF STRAIN

Marjorie Cantor (1983), conducted a study that involved interviewing caregivers over a two week period to determine quality of relationships, strains of caregiving and adjustments in lifestyle. There were four types of primary caregivers being interviewed: spouses (33%), children (36%), relatives (19%) and friends or neighbors (12%). It was found that spouses reported the highest level of stress. Their household incomes are the lowest and they are very likely to be very old themselves. Because they are older, they may be in poor health themselves. Eighty-four percent viewed their own health status as being poor or fair. In this study the sample size was a little different. Females are usually the largest group of caregivers. In Cantor's study, it was a little different, over 50% of the spouse caregivers were male. They provide personal care, shop and cook, for many men, this is a role reversal. Children caregivers were mainly married women (75%). The age

range for these children was between 40 and 59 years with ten percent being over 60 years. In comparison, the children caregivers had the highest socioeconomic status. When quality of relationship is looked at it is found that there is an inverse correlation between closeness of relationship between caregiver and receiver and the ability to get along. Friends and neighbors reported they get along best while children came in last. This was attributed to intergenerational differences. Out of the children interviewed only 48% reported that they understood their sick parent and only 28% said they felt they were understood by their parent.

Caregivers were then questioned about eight common areas of activity and to rate them in terms of how their lives have been affected by being a caregiver. When it was determined that there had been an affect, follow up questions would be asked to determine the nature of the impact and the adjustments that have been made to help cope with the situation. The results were that all groups reported negative impacts that resulted in having to do without or give up something. Negativity varied from group to group as well as the affect it had. The impact of every day life had a positive correlation to the closeness between caregiver and receiver as well as continued involvement of the caregiver. The most common areas of complaint were those where the caregiver had to give something personal, such as free time, time to take vacations, socialize with friends or run your house.

THE EFFECTS OF CAREGIVING ON EMPLOYMENT

Another area that can be effected by caring for the elderly would be caregiving and employment. Scharlach and Boyd (1989) surveyed a major company in the southern California area. Through this survey they were able to obtain a sample of 341 employees that were currently working full time and caring for a person aged 60 or older. Subjects were asked to fill out a questionnaire that measured caregiving activities, caregiver strain

and work role impact. The results revealed that 80% of the subjects reported some degree of emotional stress. Of these subjects (80%), over 37% reported having to miss work during the past two months because of family responsibilities. About one-third of subjects reported that their job performance was effected because they were so tired due to caregiving. They also reported having to make and receive caregiving related phone calls during the past two months. Subjects reported that they were forced to turn down a change in job location, tried to change their job, missed training opportunities or worked fewer hours than they would have preferred all due to the demands of caregiving. Finally about one out of every five people sampled expressed that it was somewhat likely or extremely likely that they would have to quit their jobs to care for an elderly loved one: creating less time for themselves.

ELDERLY ABUSE

This lack of time for ones self can lead to frustration, resentment and increased stress. Perhaps the most widely cited risk factor in the elder maltreatment literature is the resentment created by the dependency of an older person on the caregiver (Kosberg, 1988). Pillemer and Finkelhor (1989) conducted a study where they compared two groups to determine if elderly abuse results from the burden and stress. The groups were 61 elderly people who had been identified through interviews as abused or neglected. The other was a control group of 215 who experienced no abuse. Maltreatment was defined in terms of physical abuse, neglect and chronic verbal aggression. This study did not deal with material abuse, such as theft or misuse of elderly funds. To measure caregiver stress each subject was interviewed to determine: 1) Their general health and the number of days in the past year that they were unable to perform their usual daily activities due to illness; 2) Next the respondents were asked to complete an ADL scale which determines the extent to which they were unable to perform nine ADLS; 3) The last was a measure

of caregiver stress that assessed how much the respondent was dependent upon the caregiver (abuser) in areas of cooking, cleaning, finances, household repairs, social life, personal care and transportation.

This study yielded an estimate of 32 victims per 1000 elderly people in the area that the sample was obtained. This study contradicted many studies on abuse, instead of finding that children are the most common perpetrators, it was determined that the respondents spouses were most often the abuser. Sixty percent of physical abuse and 58% of all abuse was inflicted by spouses. Pillemer and Finkelhor (1989) determined that the items that distinguished the abused group were those that involved the caregiver and his or her behavior or circumstances, not things that deal with the care receiver. It was found that those who abuse were more likely to have some manifestation of socioemotional maladjustment. The abusing caregivers were more likely to be dependent upon the care receiver financially, in comparison to the control group. Abusers were also more likely to have suffered from two life stresses in the past year.

Overall, this study did not go along with the stereotypical caregiver stress and burden causing abuse, but rather the abuse seems to be related to the abuser's problems and dependency, not the needs of the elderly. Pillemer and Finkelhor go on to stress the importance of long term care and caregiver support groups. Reducing caregiver stress before it becomes a major problem may be helped by nursing home placement.

CHAPTER 3

DESIGN AND MEASUREMENTS

SAMPLE

Subjects were 20 people who were admitting either their mother or father into a nursing home. Subjects must have had their loved one living with them for at least one year prior to placement and must be admitting them directly from home. Subjects there were 16 whites and 4 blacks, who ranged in age from 65 to 73. They were selected through the admissions department the day of admission for their parent.

PROCEDURE

Subjects were approached in the admissions office and it was explained that they were needed as a subject for a Master's thesis on anxiety/stress produced by being the primary care provider for the past year and finding the appropriate nursing home. Subjects were informed that after filling out the initial questionnaire that day, they would be contacted again in one month to complete the same form again. They were informed of the results at a later date.

Participation was voluntary and confidentiality was guaranteed.

Each subject was presented with the following: 1. Institute for Personality and Ability Testing Anxiety Scale.

The subjects were instructed on how to mark the research instruments and given an unlimited time to finish.

MEASURES

The Institute for Personality and Ability Testing Anxiety Scale was chosen because it includes the best 40 anxiety items among several thousand personality items that have been examined up until now. It is not only used for initial diagnosis, but also in follow-ups as a "clinical thermometer" for charting progress or change of level (Krug, Scheier, and Cattell, p. 5). It scores high on reliability and validity.

A test-retest coefficient of .82 has been reported for a sample of 94 university students. This date is unpublished and was provided by Professor John R. Nesselroade, Pennsylvania State University (Krug, Scheier, and Cartell, p. 25). The validity of this test was looked at from three sources: 1. How well the test score correlates with the pure anxiety factor it was designed to measure; 2. how well the test score corresponds with clinical judgment regarding anxiety level and; 3. how well the test score relates to other questionnaire measures of anxiety. When these three independent ways are looked at, the central core of the anxiety concept approaches .90 (Krug, Scheier, and Cattell, p. 25-27).

ANALYSIS

Differences in anxiety levels for individual subjects will be calculated. These scores will then be used to compute the main difference for the total group of 20 subjects.

A repeated measures T-Test will be computed on the pre and post test to assess the hypothesis.

SUMMARY

In Chapter 3, sample, procedure and measurements for the study were discussed. This chapter is also informative for Chapter 4, because these analysis are in essence the meaning behind the entire study. The results will be discussed in Chapter 4 and any significance will then be shown.

CHAPTER 4

RESULTS

When the data collected from subjects ($n = 20$) taking the IPAT at the time of admitting their loved ones and then again one month later, it revealed by using the Pearsons r , a significant nonzero correlation in the population with $r = .86$, $p < .01$.

By using a repeated measures T-test we are safely able to reject our null hypothesis with $t = 2.994$, $p < .01$. From these results it is safe to assume that caregivers experience a decrease in anxiety after their loved one has been in a nursing home for one month.

The subjects can be described as predominantly female with only two men out of the sample of twenty. The main age for subjects was 69.5.

DISCUSSION

After collecting and analyzing the data, the results were not too surprising. The subjects were followed during the month between the two tests. Through frequent contact with these subjects the researcher found that nursing home placement consisted of not just finding a home and dropping mom or dad off, but of four equally important parts. Making the decision, implementing the decision, adjusting to the decision and learning to live with the decision. The anxiety that is experienced during the first two parts can be phenomenal. Making the decision to institutionalize a parent is realizing that love is doing what a person needs, not necessarily what the person wants.

When people are born, the doctor cuts the umbilical cord and frees us from our mother - physically. Emotionally many people never cut the cord. At sixty-five years old many men and women are still trying to please their parents. It is these people who have never found the freedom to be themselves. These are the people who are on a constant guilt trip and who are essentially trapped. They most likely have a much higher anxiety level, one that is not so easily lowered.

The nursing home from which the sample was collected has a unique support group run by a psychologist who specializes in geriatrics. This group consists of family members who are having some difficulty letting go, feeling guilty or wondering if they had done the right thing. Out of the 20 subjects, 18 subjects attended these weekly groups. Subjects expressed, after several sessions, that they learned how to handle the guilt trap that so many parents catch their children in. They learn that 1. many people have experienced a life long pattern of guilt that is only exacerbated after nursing home placement. 2. Guilt is rarely logical. 3. Not all guilt comes from the parent, it often comes from turning anger inward to focus on themselves and 4. Guilt is never constructive, it creates misery where no one is helped, nothing is changed and no one is better off.

Not all parents in nursing homes will use guilt. However, many will use it and most will be successful. Children already feel a sense of frustration, fear and failure. They feel as though they have rejected their parents by placing them in a nursing home. This makes the children ready for guilt trips. Adjustment to placement is a process that both the parent and the child must go through. Some make the transition easier than others.

Age obviously brings changes, many cause insecurity and fear. Children need to understand how these changes are affecting their parents. Through therapy, the child should be able to care and give themselves, but not allow any guilt trips. They give what they feel they can give, not feeling guilty about not doing more. They understand that love is tough.

CHAPTER 5

SUMMARY AND CONCLUSIONS :

The purpose of this study was to discuss the relationship between nursing home placement and anxiety levels of the people placing their loved ones. The study used 20 subjects from a nursing home in southern New Jersey. Subjects were people who had cared for a parent at home for at least one year prior to placement. Subjects were administered the IPAT anxiety scale on the day of placement and again one month later.

Relationships were shown through T-Tests and correlation coefficients. This study indicated that there were significant changes in anxiety levels of subjects after a one month period.

IMPLICATION FOR FUTURE RESEARCH

This study opens many doors for future research. Researchers may want to investigate:

1. The relationship between guilt levels and anxiety levels.
2. The effects of support groups on anxiety levels and guilt.
3. The differences in anxiety levels of men versus woman.
4. The relationship between parent and children and how it effects anxiety levels.
5. Differences in anxiety levels in subjects having their parent live with them for varied amounts of time.

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