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THE ASSESSMENT OF CAREGIVER BURDEN AMONG PARTICIPANTS IN  
THE HOME BASED PRIMARY CARE PROGRAM

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Dennis Kaney and Ryan Sanft

June 2000

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## ABSTRACT

With the increase in the elderly, Americans' caregiver roles and responsibilities are also on the rise. Developing with this increase is the growing problem of caregiver burden. The Loma Linda V. A. Hospital has developed a service known as the Home-Based Primary Care program designed to combat caregiver burden. Studies were conducted among caregiver participants in this program in an effort to evaluate overall levels of burden and the program's efficiency at meeting caregiver needs. Overall this program provides a useful model for future programs aimed at reducing caregiver burden. Limitations that can be improved, however, include consistency in scheduling, reliable staffing, and continuity in care.

## ASSIGNED RESPONSIBILITIES

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:  
Assigned Leader - Dennis Kaney  
Assisted by - Ryan Sanft
2. Data Entry and Analysis:  
Assigned Leader - Dennis Kaney  
Assisted by - Ryan Sanft
3. Writing Report and Presentation of Findings:
  - a. Introduction and Literature  
Assigned Leader - Ryan Sanft  
Assisted by - Dennis Kaney
  - b. Methods  
Assigned Leader - Dennis Kaney  
Assisted by - Ryan Sanft
  - c. Results  
Assigned Leader - Ryan Sanft  
Assisted by - Dennis Kaney
  - d. Discussion  
Assigned Leader - Ryan Sanft  
Assisted by - Dennis Kaney

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## CHAPTER ONE: INTRODUCTION

Throughout the history of mankind, a fundamental truth that has remained constant is that people need other people in order to survive. Put in simpler context, the human condition requires its members to take care of each other. Likewise, as people grow old, they sometimes have problems taking care of themselves, so they turn to their families to take care of them.

Of the nearly 26 million people over the age of 65 in today's society, 23 percent have functional limitations (Romaine-Davis, Boondas, & Lenihan, 1996). This requires many members of the elderly population (especially those over the age of 70), to rely heavily on their families to assist them in daily living tasks. Caring for an elderly family member at home may cause an intolerable strain, referred to as caregiver burden (Montgomery, Gonyea & Hooyman, 1985; Pearlin, Mullin, Semple, & Skaff, 1990; Vrabec, 1997). This stress is a product of the emotional, physical, and financial burdens placed upon the caregiver in response to offering care (Romaine-Davis, Boondas, & Lenihan, 1996).

This research project was designed to assess caregiver burden among participants of the Home-Based Primary Care (HBPC) program at the Jerry L. Pettis Memorial V. A. Hospital in Loma Linda, California. The HBPC program provides a good atmosphere for conducting



research on caregiver burden for three main reasons. First, it is a direct program aimed at aiding primary caregivers in their efforts to provide quality care to the veteran. This created a useful sample population for obtaining data. Second, the program endorses treating the person in the environment as a principal dimension of service and boasts high rates of success regarding treating the person in the environment (PIE). Since one element of this project examines the association between homebound services and caregiver burden this was particularly important to our study. And third, unlike most conventional home-care services, which aim only at meeting the needs of the patient, the HBPC is designed to offer support to the caregiver as well.

#### Historical Background of Home-Based Primary Care

The HBPC program was designed as a community-interactive case management program with chronically ill or at-risk homebound veterans in mind. The HBPC bridges the gap between the veteran and the Medical Center and also serves as an important support network, linking the caregiver to viable community resources needed for ensuring adequate home based primary care for the patient. Its main focus is to provide support to the veteran and caregiver in order to help the veteran avoid

hospitalization and remain at home as long as it is safely possible.

Specific service objectives of the HBPC program are:

- 1) Providing a coordinated team consisting of a nurse, social worker, rehabilitation therapist, dietitian, and pharmacist to the primary patient and caregiver.
- 2) Increasing the ability of the Medical Center to assist and coordinate home care service by providing a medical consultant whom will meet with the veteran's primary physician.
- 3) Providing education to the patient and the caregiver relating to health care needs.
- 4) Providing referrals to community home health care agencies when indicated to supplement the care provided by the primary caregiver. These agencies work in partnership with the HBPC team.
- 5) Providing clinical monitoring of medications of all HBPC patients by the HBPC pharmacist.

Currently there are 42 nationally recognized HBPC programs in V. A. medical centers. The HBPC program at Loma Linda provides services to an average of 105 patients residing within a 60-mile radius of the hospital. At the time the research project was conducted there were 122 patients participating in the program. The typical HBPC patient was 66 years or older and functionally limited in two or more activities of daily living. Usually he is bedridden and often unacceptable for skilled nursing placement due to the intensive level of care required.

The HBPC is available to veterans who are receiving their primary medical care through the Loma Linda V. A. Medical Center. Today there is an increasing demand on utilizing the services offered by this program in discharge planning, as an alternative to nursing home placement. This accounts for a decrease in the number of patients discharged to nursing home facilities and increases the number of homebound patients and HBPC candidates.

According to V. A. literature, the HBPC program is congruent with the national statistics on home care providers. Most of the caregivers in the program are informal family members. The benefits of such a program are based on three assumptions.

First, living in the community is preferred to institution life, as most aged people prefer to stay in their homes if at all possible. Second, living at home is cost effective and often 10 times cheaper than institutional residency. According to past V. A. literature, a person can stay in their home at an average daily cost of \$7.20, compared to \$72 per fee the V. A. would have to pay a contracted skilled nursing facility. Third, the quality of care and desire of caregivers to provide meaningful service and support in the home is superior to an institution.

## Problem Statement

Current literature on elderly care states the majority of care offered to the elderly population is through the informal services of family members (Coward & Quadagno, 1996). But to what extent or at what cost to the family member or primary provider does this emphasis on care come?

It has been reported that family caregivers have poorer health than the average population (Stone, Cafferata, & Sangl, 1987). It is also feared that many of the social, economic, and emotional problems faced by family caregivers may result in a decreased quality of care offered to the elderly person receiving care. In some instances these problems lead the caregiver to feel "burnt-out" and increase the likelihood that neglect and abuse will occur (Smith, Tobin, Robertson-Tchabo, & Power, 1995).

Because these issues appear relevant to the growing population of elderly individuals found within the HBPC program, this project was designed to address two primary questions. First, to what extent do HBPC primary caregivers suffer from caregiver burden and strain? And secondly, how effective is the HBPC program at meeting the needs of the primary caregiver (especially in relation to caregiver burden and strain)? Our intent is to understand the scope of caregiver burden among this population and

determine what other support programs and interventions could be applied or modified by the HBPC in order to offer improved support to the primary caregiver.

#### Definition of Terms

In order to clarify the meaning behind recurrent key terms found within this study, we offer the following definitions.

##### Primary Caregiver:

Primary caregiver is defined as one who is principally responsible for providing care, coordinating needed resources, and lives with the dependent elderly person.

##### Care Recipient:

The care recipient is a person who is no longer able to take complete control of his/her life and for some reason needs major assistance from other people in order to perform activities and tasks associated with daily living (Springer & Brubaker, 1984).

##### Strain:

Strain is defined as enduring problems that have the potential for arousing threat (Robinson, 1983). In this paper, strain and stress are interchangeable concepts.

##### Burden:



This by definition is a summation of the psychological, physical, and financial costs of caregiving.

#### Support Programs:

There are four basic types of caregiver support offered by the HBPC: 1) education and training; 2) mutual aid and self-help; 3) counseling; 4) respite in some form.

#### Literature Review

Only in recent history has caregiving been defined as a social problem (Pillemer, 1996). According to current findings, the problem of elderly caregiver burnout is still a new concept. Pillemer (1996) states, "as research studies have proliferated, there has been a persistent sense that in this area we have furious effort with relatively little to show for it".

Literature does support however, the notion that females have traditionally been the family caregivers. Changes in the work force are now requiring middle-aged wives, daughters, and daughter-in-laws to assume roles of paid workers and caregivers (Eaulieu & Kaprinski, 1981; Brody, 1981, 1985; Cantor, 1983; Clark, 1983; Crossman, London & Barry, 1981; Farkas, 1980; Soldo & Myllyuoma, 1983, Zarit, Reever & Bach-Peterson, 1980, Atchley, 1997; Romaine-Davis, Boondas, & Lenihan, 1996; Smith, Tobin, Robertson-Tchabo, & Power, 1995; Cowart & Quadagno, 1996).

In most situations the primary care giver is the patient's wife. This is likely due to the fact that women generally live longer than men and tend to be younger than their husbands to begin with (Atchley, 1997). "Most men age 65 or older are married with a spouse present . . . even at age 75 and over 66.7% of the men are living with a wife" (Beaulieu & Karpinski, 1981, p. 556).

Brody (1985) concluded that many women commonly referred to as the sandwich generation carry the burden of caring for aging parents, as well as their own children. This causes them to feel the impact of stress.

A growing trend exhibited in society is that a larger number of older people have become caregivers due to the increase in longevity. As people live to be 80 to 90 years old, the caregivers themselves are elderly (Atchley, 1997). This causes the effects of debilitation to enter in as a latent effect diminishing the quality of care provided. Older women caring for disabled spouses have been identified as a particularly high-risk group of caregivers with special needs and problems. Wives with low morale scores have been seen as particularly in need of support if institutionalization of the husband was to be avoided.

There have been very few studies conducted specifically on the impacts of aging on the caregiver. Four key studies conducted in the early 80s that looked at

home care of the dementia patient were conducted by Beaulieu & Kaprinski (1981); Crossman, London & Barry (1981); Fengler & Goodrich (1979) and Snyder and Keefe (1985). A recent study by Uhlenberg (1996) reached the same conclusions as the previous four studies. It found that many of the needed services of elderly people can't be met by their family member (spouse) because as they get older, they are less likely to be capable of providing adequate care. The study concluded that as the population of aging Americans increases, the use of formal caregivers is the best solution to avoid burden and strain felt by loved ones (Uhlenberg, 1996).

The primary caregiver takes on a complex role without the aid of skilled education, colleagues, or professional help to handle the heavy emotional load. This causes emotional strain. Significant associations between increased work and increased burden have been shown in many studies (Bull 1990; Casert, Lund, Wright & Radburn, 1987; George, 1987; George & Guwyther, 1986; Given, Stommel, Collins, King & Given, 1990; Miller & McFall, 1991; Montgomery, Gonyea & Hooyman, 1985; Pratt, Schmall, Wright & Cleland, 1985; Robinson, 1990; Scott, Roberto, & Hutton, 1986, Zarit, Reever, & Bach-Peterson, 1980).

According to current findings, family caregivers often have higher levels of depression, experience



feelings of helplessness, lowered morale, emotional exhaustion, have lower levels of income, and are generally unhappier with life than the general population (Brody, 1985; Romaine-Davis, Boondas & Lenihan, 1996; Clair & Fitzpatrick, 1995).

Penning (1995) determined that the relationship between caregiver burden and the use of home health services among older adults with cognitive impairment is weak. Most caregivers are unaware of the services offered by home health services. Penning's conclusion confirms the need for better services for caregivers who are under stress. The current emphasis on community-based long-term care has generated increased interest in the crucial role of the caregiving support network of the dependent elderly.

The effective management of health problems of older adults depends greatly on the provision of assistance to them by their family members (Penning, 1995; Romaine-Davis, Boondas & Lenihan, 1996; Clair & Fitzpatrick, 1995). Education and support groups can enable these family members to better carry out their responsibilities.

Social support is an important need of caregivers. It moderates the perception of burden (Given & Given, 1991; Wright, Clipp, & George, 1993). Significant associations between greater support and reduced burden have been shown in many studies (Bull 1990; Casert, Lund,

Wright & Radburn, 1987; George, 1987; George & Guwyther, 1986; Given, Stommel, Collins, King & Given, 1990; Miller & McFall, 1991; Montgomery, Gonyea & Hooyman, 1985; Pratt, Schmall, Wright & Cleland, 1985; Robinson, 1990; Scott, Roberto, & Hutton, 1986, Zarit, Reever, & Bach-Peterson, 1980). Furthermore there is a direct association between providing support for family caregivers and reducing burden (Atchley, 1997; Barnes, et al, 1981; Brody 1981; Cantor, 1983; Clair & Fitzpatrick, 1996; Cohen, 1983; Cowart & Quadagno, 1996; Crossman, London & Barry, 1981; Getzel, 1981; Hartford & Parson, 1982; Lazarus, 1981; Penning, 1995; Perlman, 1983; Portnow & Houghton, 1987; Smith, Robertson-Tchabo & Power, 1996; Soldo & Myllyuoma, 1983; Waslow, 1986; Wetle & Evans, 1984; Zarit, 1986).

Although these reports show significant correlations between caregiver burden and caregiver roles, most studies have not been controlled, nor have they used valid and reliable instruments for measuring participant change (Vrabec, 1997).

Furthermore, current studies do not show a direct correlation between the availability of support programs like the HBPC, and the caregiver's continuing ability to cope with the demands of caregiving. Evidence does indicate however that educational and supportive agencies do have an association with relieving burden and strain in

caregivers' lives (Crossman, London & Barry, 1981; Lazarus, et al, 1981; Penning, 1995; Tebbstedt, Harrow, & Crawford, 1996).

## CHAPTER TWO: METHODS

### Design

This study was a descriptive survey administered through telephone conversations with participating HBPC care providers. It utilized two standardized measures, the Caregiver Burden Inventory (Novak & Guest, 1989), and the Client Satisfaction Questionnaire (Atkinson, Hargreaves, & Nguyen, 1979). (See Appendix A) Additional questions concerning demographics, caregiver morale and suggested improvements in services were also asked.

Novak and Guest's (1989) multidimensional Caregiver Burden Inventory consists of 24 items with responses on a Likert scale ranging from 1, strongly disagree to 4 strongly agree. These items fall into five categories or factors related to caregiver burden including time dependence, developmental, physical, social, and emotional burden. Five interpretable factors result from the analysis.

A subject's score on each factor could range from 0 to 20 except for factor 3 (with only four items), where scores could range from 0 to 16. Factor 3 scores were adjusted by multiplying the obtained score out of 16 by 1.25 to give an equivalent score out of 20.

Factor 1 - Time Dependence Burden describes the burden due to constraints on the caregiver's time.

Caregivers are often burdened by not being able to get away to take a break or have time to themselves. The constant attention and feeling of responsibility places stress on the caregiver. Items like, "My care receiver is dependent on me" or "I don't have a minute's break from my caregiving chores" reflect their level of burden.

Factor 2 - Developmental Burden describes the caregiver's feelings of being "off time" in their development with respect to their peers. Few people have prepared to be caregivers and once they enter this role they often do not receive much support. Caregivers see their peers enjoying their later years as they expected, but unlike their peers, they feel continued anxiety and strain. Items like, "I feel that I am missing out on life" and "I expected things would be different at this point in my life" reflect this feeling of burden.

Factor 3 - Physical Burden describes caregivers' feelings of chronic fatigue and damage to physical health. Caregivers run a high risk of physical illness due to caregiving. Items like, "I'm not getting enough sleep" and "Caregiving has made me physically sick" reflect caregivers' feelings of physical burden.

Factor 4 - Social Burden describes caregivers' feelings of role conflict. A caregiver may argue with a spouse or with other family members over how to administer to the veteran's needs. Caregivers often feel neglected

or unappreciated by others. They may also have to limit the time and effort that they put in relationships or their jobs. Items like, "I don't get along with other family members as well as I used to" and "I don't do as good a job as I used to", reflect caregivers' feelings of social burden.

Factor 5 - Emotional Burden describes caregivers' negative feelings towards their care receivers, which may stem from the care receivers' unanticipated behaviors. Caregivers may feel guilty about these socially unacceptable feelings. Items like, "I resent my care receiver" and "I feel angry about my interactions with my care receiver" reflect these feelings of emotional burden.

The Caregiver Burden Scale has acceptable internal consistency reliability coefficients (Cronbach's Alpha) ranging from .73 to .86. The internal reliability coefficient of each subscale of the Caregiver Burden Scale is time-dependence burden (.85), developmental burden (.85), physical burden (.86), social burden (.73) and emotional burden (.77) (Novak & Guest, 1989).

The Client Satisfaction Questionnaire is an 8-item, easily scored and administered measure that is designed to measure client satisfaction with services. Corcan & Fisher (1987) state, "The CSQ-8 has been utilized by a number of populations. It is known to be very reliable and has excellent internal consistency with alphas that

range from .86 to .94 in a number of studies." Test-retest correlations were not reported.

The CSQ-8 is also known to have a very high concurrent validity. The CSQ-8 has also demonstrated moderate correlation with a number of other outcome variables, thus suggesting a modest correlation between satisfaction and treatment gain (Corcan & Fisher, 1987). For our study we have modified this instrument to pertain to the caregivers' opinion of the HBPC program.

#### Sample: Description of Target Population

The sample for this study consisted of 30 caregivers of veterans who are suffering from a range of illnesses who were receiving assistance from the Home Based Primary Care Program (HBPC). At the time the study was conducted the HBPC program had a population of 122 members receiving services. From this population 70 individuals had a reported primary caregiver. Among these caregivers we were able to successfully contact 30 individuals willing to participate in the study.

## Procedure

The study was conducted over a period of one month on four separate occasions. The average time it took to conduct the questionnaire was around twenty-five minutes. While conducting the surveys the interviewers followed a standard telephone greeting and explanation script (see Appendix B) explaining the nature of the survey and the caregiver's rights for participating, including informed consent, confidentiality, and anonymity.

At the conclusion of the survey each participant was thanked and informed that they would be receiving a debriefing letter in the mail (see appendix C), and a bookmark as a token of appreciation for participating in the study.

## Data Analysis

Data analysis in this study was both descriptive and explanatory in nature. The data analyzed addressed the issue of whether a significant amount of burden exists among the clientele of the HBPC program and which caregivers are at risk of burnout. Descriptive analysis included univariate statistics such as frequency distribution, measures of central tendency and distribution. Bivariate statistics included t-tests, chi-square, and Pearson product moment correlations which were used to evaluate association between two variables. In



comparing the psychological distress of caregivers, a series of t-tests were used. For explanatory analysis, a series of multivariate analyses were done to evaluate the relationship between the multiple independent and dependent variables. Multiple regression and multivariate analysis was used to evaluate the specific contribution of each of the independent variables to the dependent variables.

## CHAPTER THREE: RESULTS

### Demographic Results

The majority of the caregivers 86.7 percent (N=26) were women and 13.3 percent (N=4) were men. Caregivers' ages ranged from 28 to 87 years with a mean age of 63.03. Of the caregivers, 26.7 percent (N=8) were African American, 3.3 percent (N=1) were Asian/Pacific Islander, 6.7 percent (N=2) were Hispanic/Latino/Chicano, 53.3 percent (N=16) were White, and 10 percent (N=3) were Native American.

Among the caregivers 3.3 percent (N=1) had a junior-high education, 50 percent (N=15) graduated from high school, 33.3 percent (N=10) had some college, 10 percent (N=3) were college graduates, and 3.3 percent (N=1) were a college post-graduate.

There were 16.7 percent (N=5) who were receiving income for their caregiving responsibilities and 83.3 percent (N=25) who were not receiving income. Ten percent (N=3) of the caregivers were employed part-time outside of their caregiving responsibilities and 90 percent (N=27) were not employed.

The caregivers' relationship to the caregiver consisted of 73.3 percent (N=22) being the spouse, 10 percent (N=3) being the son, 3.3 percent (N=3) being the daughter, 3.3 percent (N=1) being a girlfriend or boyfriend, and 10 percent (N=3) being no relation.

Among the caregiver's 3.3 percent (N=1) reported having poor health, 30 percent (N=9) reported having fair health, and 66.7 percent (N=20) reported having good health.

Among the care recipients 90 percent (N=27) were men and 10 percent (N=3) were women. The care recipient's ages ranged from 28 to 88 with a mean age of 69.40. Of the recipients, 20 percent (N=6) were African American, 3.3 percent (N=1) were Asian/Pacific Islander, 10 percent (N=3) were Hispanic/Latino/Chicano, and 66.7 percent (N=20) were White. The caregivers reported the recipient's health as 66.7 percent (N=20) as being poor, 20 percent (N=6) as being fair, and 13.3 percent (N=4) as being good.

### Survey Findings

The results of our study mean scores and standard deviations of the caregiver burden factors were: Factor 1 (time dependence) = 12.4 (SD 2.67); Factor 2 (developmental) = 12.79 (SD 3.34); Factor 3 (physical) = 9.43 (SD 2.6); Factor 4 (social) = 8.8 (SD 3.31); and Factor 5 (emotional) = 12.38 (SD 2.63). Independent sample T-tests between the demographic variables and the caregiver burden factors were run. One significant relationship was found while comparing caregiver employment with social burden ( $t=-3.181$ ,  $df=26$ ,  $p=.004$ ).

There was no significance between any of the other factors.

While comparing caregiver gender to the caregiver burden factors we found only one variable, time dependence, was significant ( $t=3.846$ ,  $df=8$ ,  $p=.010$ ). There was no significance among the other factors.

While comparing the caregivers' health to the caregiver burden factors showed a relationship between developmental burden ( $t=2.368$ ,  $df=27$ ,  $p=.025$ ), social burden ( $t=4.309$ ,  $df=26$ ,  $p=.000$ ), emotional burden ( $t=4.408$ ,  $df=28$ ,  $p=.000$ ), and physical burden ( $t=3.457$ ,  $df=28$ ,  $p=.002$ ). There was no significance among the other factors.

Other demographic variables (including caregiver ethnicity, caregiver education level, caregiver income, caregiver relationship, and caregiver health) had no significant relationship with the caregiver burden factors.

Pearson correlations between the caregiver burden factor totals were run. Significant relationships were found between time dependence burden and developmental burden ( $r=.603$ ,  $p=.001$ ), as well as time dependence burden and physical burden ( $r=.546$ ,  $p=.002$ ).

Significant relationships were found comparing developmental burden to social burden ( $r=.489$ ,  $p=.010$ ), and comparing emotional burden ( $r=.536$ ,  $p=.003$ ) to

physical burden ( $r=.680$ ,  $p=.000$ ). Lastly, there was significance while comparing social burden to emotional burden ( $r=.773$ ,  $p=.000$ ). There was no significance between any of the other factors.

Independent sample T-tests between the client satisfaction total scores and the demographic variables found only one relationship approaching significance with caregiver employment ( $t=1.87$ ,  $df=28$ ,  $p=.072$ ). No other demographic variables had a significant relationship to client satisfaction.

There was significant relationship between client satisfaction and both social burden ( $r=-.472$ ,  $p=.011$ ) and physical burden ( $r=-.443$ ,  $p=.014$ ). There was no significant relationship between any of the other caregiver burden factors and client satisfaction.

## CHAPTER FOUR: DISCUSSION

The findings of this study suggest that family caregivers in the HBPC due face a significant amount of caregiver burden and strain. In most cases this burden is the direct result of the amount of responsibility placed upon a caregiver. Likewise, the HBPC program appears to be instrumental in relieving significant levels of burden and strain.

Demographic variables of both the caregiver and care recipient were analyzed in association with caregiver burden factors and client satisfaction factors with services they received from the HBPC program. The findings indicate that those caregivers who were not employed outside of their caregiving responsibilities suffered from social, emotional, physical and time dependence burdens.

This suggests that these individuals lack the social support that accompanies having a job. As a result these isolated individuals experience depressive symptoms associated with caregiving i.e., isolation, helplessness, low morale, and emotional exhaustion.

By correlating caregiver health with physical burden we found that those caregivers suffering with health problems were not getting enough sleep and were physically tired, which was having an impact on their health. This

is not surprising since most of the caregivers in our study were over the age of 65.

Our findings suggest that because they were suffering from debilitating health themselves caregiving became extremely difficult. This finding is congruent with findings found in similar studies. As people grow older with less contact to needed support groups, they become physically unable to bear the weight of caring for themselves and another family member (Uhlenber, 1996; Romaine-Davis, Boondas & Linehan, 1996; Clair & Fitzpatrick, 1995).

The findings also indicate that caregiver gender is significantly related to time dependence burden. Our study found that women are far more likely to feel heavily relied upon by the veteran than are male caregivers. This suggests that women, due to the multi-faceted complex roles they attempt to manage, feel strained due to having the majority of their time being devoted to the care and management of the care recipient.

This association is typical of those found in most studies on caregiver burden and only justifies the idea that burden and strain are a direct result of being required to fulfill many complex roles, like, being a housekeeper, a mother, babysitting grandchildren, and taking care of your mother or father as well (Brody, 1985).

When comparing the caregiving factors to each other, our findings indicated significant relationships between the different types of burden. When caregivers were suffering from time dependence burden they also suffered from developmental and physical burden. They felt like they were missing out on life and were tired most of the time. When caregivers were suffering from developmental burden they also suffered from emotional, social, and physical burden. Lastly, when caregivers suffered from social burden they also suffered from emotional burden. These findings support the fact that caregiver burden and strain is multi-faceted and feeling strain in one area may cause strain in another area as a result.

Length in time at answering the survey questions also provided insight into caregiver burden. Although the questionnaire could be administered in less than 5 minutes, the average telephone conversation lasted around 25 minutes. Most caregivers were lonely or frustrated over their caregiving role and needed to verbalize their concerns with someone. Feeling uncomfortable about sharing their concerns with family or close friends, the survey questionnaire process provided a welcomed outlet for them to voice their opinion. Thus, it was not uncommon for a caregiver when asked, "Do you strongly agree, agree, disagree or strongly disagree?" to give their response followed by, "Now let me tell you why!"



### HBPC Program Effectiveness

Findings for program effectiveness indicated that all participants were satisfied with the HBPC program. Caregivers who worked full-time taking care of the recipient were satisfied the most with the services provided.

There was a significant relationship between client satisfaction and both social and physical burden. Caregivers reported that the services allowed them some time to rest and decreased the strain on their marriage.

These findings indicate that the HBPC was beneficial in relieving not only physical factors of burden and strain but emotional and social factors as well. Because caregiver burden and strain increase when the amount of caregiver responsibility increases, the HBPC service providers sent out to the homes also aided the caregiver by providing emotional and social support as well.

### Limitations

The data for this study were gathered from the HBPC roster. This roster didn't tell us how long a caregiver had been providing care nor did our survey address this issue. It would have been beneficial to explore how long the caregiver had been taking care of the care recipient. This could be an important aspect of the amount of burden

a caregiver is under. The process of developing burden and strain is usually built up over time. Being able to distinguish the amount of burden each participant was under to determine if it were built up over time would've added useful dimensions to our analysis.

Our study was also restricted to a relatively small sample size. This may possibly limit the study's generalizability, as well as, true outcome measures. Past studies, which dealt with larger sample sizes, appear to show less burden and strain than our results (Novack & Guest, 1989).

### Implications

The findings in this study have implications pointing to the need for more resources like the Home Based Primary Care program for combating caregiver burden and strain. This program appears to be successful at alleviating many of the symptoms found across several different factors of burden and strain.

When asked what could be changed about the HBPC three repeating opinions were rendered. First, the program's nurses need to be more consistent at coming out on the date and time they stated they would. Too often appointments were made and then cancelled by the HBPC services. It was also not uncommon for the nurses to skip

their appointments without informing the participants that they weren't coming out. When this occurred, it only added to the symptoms of burden and strain.

Second, many participants stressed the need for consistent care providers. Often the program would send out different nurses switching them regularly. This forced the family caregiver to have to re-train the nurse about the needs of the veteran. It also added confusion and frustration because once the family members became comfortable with a nurse, they would switch nurses.

The third area where participants felt the program could improve was continuity of care. Often the HBPC service providers would start out vigorously at their duties and then over time become lazy and unconcerned about the quality of care provided. This points to burden and strain on the part of the HBPC provider and points to the importance of knowing how long a person has cared for a care recipient.

The findings in this study indicate that caregiver burden is a real issue felt by all caregivers in one form or the other. As the number of people growing old increases, so too will the need for quality of care in educating people on how to best meet the needs of providing care for the elderly as well as combating the

symptoms of caregiver burden and strain. Programs like the HBPC are in the forefront in educating family members on how to become better caregivers.

As this study was in its final editing stages, the authors were informed that the HBPC program at the Jerry L. Pettis Memorial V. A. Hospital was being canceled due to cost effectiveness!

Because qualified professional care such as that provided by the HBPC is so expensive, it is unlikely that many members of the growing aged society in America will receive formal aid or the needed educative assistance. To help alleviate this, more studies on educative services for family members are needed in the future and will be a helpful tool at forming a cost-effective system of combating the ever growing threat of caregiver burden and strain.

## APPENDIX A: SURVEY QUESTIONNAIRE

1. Strongly Disagree    2. Disagree    3. Agree    4. Strongly Agree  
Factor 1 Time Dependence

1. The person I care for needs my help to perform many daily tasks.
2. The person I care for is dependent on me.
3. I have to watch the person I care for constantly.
4. I have to help the person I care for with many basic functions.
5. I don't have a minutes break from my caregiving chores.

### Developmental

1. I feel that I am missing out on life.
2. I wish I could escape from this situation
3. My social life has suffered
4. I fell Emotionally drained due to caring for my care receiver
5. I expected that things would be different at this point in my life.

### Physical

1. I'm not getting enough sleep.
2. My health has suffered
3. Caregiving has made me physically sick
4. I'm physically tired.

### Social

1. I don't get along with other family members as well as I used to.
2. My caregiving efforts aren't appreciated by others in my family
3. I've had problems with my marriage as a result of caring for this person.
4. I don't do a good as job at caregiving as I used to.
5. I feel resentful of other relatives who could but don't help.

### Emotional

1. I feel embarrassed over my care receiver's behavior.
2. I feel ashamed of my care receiver.
3. I resent the person I care for.
4. I feel uncomfortable when I have friends over.
5. I feel angry about my interactions with my care receiver.

### Program Effectiveness

1. I am happy with the services I have or am receiving by the Homebased primary care program.
2. I got the kind of service I wanted.
3. The Home based primary care program has met my needs.
4. I am happy with the amount of help I received.
5. Home based primary care program has helped me deal more effectively with caring for the person I care for.
6. Overall I am satisfied with the services I have received.
7. If I were to seek help again I would come back to this program.
8. What HBPC services do you use?
9. What could be offered in the future to help you ease your burdens?
10. Any other suggestions?

APPENDIX B: STANDARDIZED TELEPHONE SURVEY MODEL

"Hello Mr/Mrs ???

My name is \_\_\_\_\_ I'm an intern student at the Loma Linda VA Hospital where \_\_\_\_\_ Name of Veteran participating in HBPC is receiving services. Our agency recognizes research as a basic method for evaluating existing programs and developing new ways of providing more effective services for veterans and their significant others. Currently the Jerry L. Pettis Memorial Veterans Hospital in cooperation with the Social Work Department at California State University San Bernardino is conducting a study focusing on stress reduction and the effectiveness of services offered to caregivers within the Veterans Home Based Health Care program.

Because you provide care and support for \_\_\_\_\_ Name of Veteran participating in HBPC, your experiences and opinions would be of much value. May we please take a few moments of your time to ask you a questionnaire regarding the effectiveness of services offered by the HBHC program?"

If the answer is yes continue on:

After the questionnaire is completed:

"We wish to thank you for your participation in this survey and emphatically assure you that the information requested will be treated confidently by the researcher and will in no way deter the current services provided to you through the HBPC program. Likewise, your observations and comments will in no way be identified with your name to this agency. Your information will be known only to the researcher who is conducting this study and will be incorporated anonymously, with that of many other primary caregivers of HBPC participants. Once again thank you for your time and assistance in this research project."

## APPENDIX C: DEBRIEFING STATEMENT

You have just participated in a telephone survey study designed to assess the program effectiveness of the Loma Linda V. A., Home Based Primary Care program. It is hoped that this study improves the quality of care provided by the HBPC towards helping veterans and their families live better lives.

The HBPC program recognizes research as a vital asset in quality improvement and values your time and suggestions rendered. If you have any questions regarding this study and its purpose please feel free to contact Dr. Rosemary McCaslin, head research coordinator, California State University, San Bernardino, at (909) 880-5500.

Once again thank you for your participation.

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