# NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (NFCSP): ASSESSING CLIENTS' CHARACTERISTICS, PROGRAM UTILIZATION AND DIFFICULTY ACCESSING SERVICES

By

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# ABSTRACT

**Objective:** This dissertation examined the National Family Caregiver Support Program (NFCSP), assessing NFCSP clients based on their demographic and health characteristics, caregiving-related burden and circumstances, and use of program services and support, with further stratification by care recipients' dementia diagnosis. A further examination of program outcomes focused on which client characteristics were associated with deriving limited immediate and long-term benefits from program use.

**Methods:** Approximately 1,651 responses from the 2016 National Survey of Older American Act Participants-Caregiver Module (NSOAAP-CM) were used to provide a profile of caregivers who used the NFCSP. Chi-square ($X^2$) were used to assess the significance in any differences found between dementia and non-dementia caregivers, compare responses between 2016 and earlier responses (2008; n=1,623). Logistic regression was used to exam the influence of client characteristics on limited immediate and long-term benefits.

**Results:** NFCSP clients were found to be primarily White, female, daughters, married and caring for an older adult with dementia. Dementia caregivers who used the NFCSP were found to report performing more caregiving-related tasks along with higher amounts of physical strain and emotional stress and received more intensive services such as information and assistance, respite care and education/training/counseling, whose use was found to have declined between 2008 and 2016. Overall, the program is rated very highly, however variation was found among client demographic, health characteristics and use of particular NFCSP services and supports on deriving immediate and long-term benefits from the program.

**Conclusions:** Compared to broader estimates of family caregivers of older adults, NFCSP appears to provide services for more dementia caregivers and family caregivers with higher amounts of caregiver-related physical strain, emotional stress and financial hardship. Findings indicate that dementia caregivers derived immediate benefit from program use, however the program may be limited in providing them and their care recipients with long-term benefits. Additional attention directed towards minority, stressed, strained or dementia caregivers may be necessary to assess challenges and barriers in fully benefiting from the program. Future efforts should include additional questions on caregiver assessments and on NSOAAP-CM examining specific barriers or challenges in accessing services, informing strategies needed for additional program improvement.

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~ Charlene Liggins

## TABLE OF CONTENTS

## LIST OF TABLES AND FIGURES

# CHAPTER 1: INTRODUCTION

An estimated 18-40 million family caregivers of older adults provide uncompensated care for a spouse, older relative or friend (Reinhard et al, 2015; Chari et al, 2014; Spillman et al, 2014). Although many family caregivers cope well or derive benefit from their helping role (Roth et al, 2015), other caregivers may experience physical, psychological and mental stress. Family caregivers not only assume an important role within their own families but also in shoring up the long-term care system. The care provided by family caregivers can enable many older adults to remain in their homes and communities while avoiding costly institutionalization or other more expensive paid care (Spillman. & Long, 2009).

Policies and support services that target family caregivers may be delivered through a variety of strategies to help reduce the emotional and physical burdens that are often associated with caregiving. The National Family Caregiver Support Program (NFCSP), overseen by the Administration on Aging (AoA) within the Administration for Community (ACL), is one of the first and widely available federal programs that provides support to family caregivers as the primary client or consumer rather than older adults and people who are in need of care. NFCSP provides funding for states and communities to provide a comprehensive range of services and supports through an extensive aging network (NFCSP website)

While the NFCSP was originally authorized and funded by Congress in 2000 (H.R. 782, Sec. 316. 106th Cong. (2000)), there have been limited research and analyses of the program and its clientele. Only a small number of studies to date have examined the characteristics of individuals who use the NFCSP and assesed perceived benefits derived from the long-term services and supports (LTSS) that the program offers. Early studies analyzed the initial implementation of the program across states and sought the viewpoints of state and local program administrators (Feinberg, Newman & Van Steenberg, C., 2002; Feinberg & Newman, 2004; Whittier, Scharlach, & Dal Sando, T., 2005 and Feinberg & Newman, 2006). Later studies of family caregivers who sought NFCSP services had methodological limitations such as reliance on small convenience samples or focused on utilization of services within a small geographical area (Seattle area) (Chen, Hendrick & Young, 2009; Chen, 2014). Although the program annually surveys family caregivers as part a larger assessment of Older American Act (OAA) program clientele and program performance, only one ACL-commissioned research brief (Foster and Kleinman, 2011) and one peer-reviewed article (Herrera et al., 2013) have drawn upon these surveys to describe the demographic characteristics of NFCSP clients and their utilization of program supports and services using program data. Both analyses relied on data that are now more than 8 years old and neither examined differences by dementia status or attempted to associate use of specific services with program outcomes.

A more expanded study of NFCSP family caregiver characteristics, service utilization and reported outcomes would benefit ACL, policy-makers and NFCSP clients by comprehensively describing who the NFCSP serves, what service or supports are provided and what benefits might or might not be derived from the program. In 2006, NFCSP was mandated by Congress to prioritize services for family members caring for Alzheimer's disease and dementia (H.R 6197. Sec. 321. 109th Cong. (2006)). A particular focus on dementia caregivers adds to the collective knowledge of utilization and perceived impact of such services.

This study will also complement evaluation activities currently conducted by AoA. Evaluators recently focused on the administration of the NFCSP through surveys of local stakeholders to assess how the program is administered at the state and community levels (Lewin, 2016). Through a separate analysis and theoretical framework, the results of this study could complement evaluation efforts by providing the client perspective.

### Study Aims

Recognizing the expected rise in the number of older adults who will require care along with the rising costs of paid long-term care, the need to ensure sufficient support for family caregivers has never been more important. The overall goal of the NFCSP program is to enable states and local communities to offer a range of services to support family caregivers, including providing information, assistance in gaining access to additional services, counseling, training, respite care and supplemental services. Facilitating access to NFCSP program components can be effective in reducing caregiving-related burdens and avoiding or delaying the need for costlier institutional care (NFCSP website).

This study will use NFCSP client data that are collected through the annual National Survey of Annual Older American Act Participants – Caregiver Module (NSOAAP-CM) and address the following research aims:

1. Develop a recent profile of the family caregivers, notably dementia caregivers, who have received services through the National Family Caregiver Support Program using 2016 client data;
2. Compare selected client during an earlier period of the program using 2008 client data;

3. Explore the characteristics of clients who report limited immediate benefits from program use, such as difficulty accessing services, and;
4. Explore the characteristics of clients who report limited long-term benefits for themselves and their care recipient after using the NFCSP.

Results from this study can be used to inform policy-makers of program utilization and effectiveness across varying demographic populations, identify potential service gaps, and inform resource allocation and targeted outreach by state and federal program stakeholders.

## Dissertation Organization

This dissertation is organized into six chapters (including this introductory chapter). Chapters 2, 4, and 5 will be presented as three manuscripts that may be submitted to scientific journals. Chapter 2 (manuscript #1) provides background information and literature concerning family caregivers' informational and services needs and utilization of long-term care services and supports. This chapter also includes a description the NFCSP's services and supports and earlier research focusing on the program implementation and impact.

Chapter 3 provides a description of the study design and methodology including a description of the primary survey instrument, a theoretical framework to organize and operationalize survey responses and statistical methods used to analyze survey data based on the presented research aims.

Chapter 4 (manuscript #2) provides a description of the demographic and health characteristics of family caregivers who use NFCSP services and supports. Findings from manuscript #2 provided a demographic profile of the NFCSP clients, and highlights the higher levels of responsibilities, emotional stress and physical strain reported by dementia caregivers compared with non-dementia caregivers who use the NFCSP. Dementia caregivers are also more likely to receive the more intensive of set of core services and supports. Findings also indicate that additional Congressional requirements and a stagnant budget may have impacted the use and availability of certain services over the last few years.

Chapter 5 (manuscript #3) explores any variation among client characteristics in deriving immediate and long-term benefits from using the NFCSP. Clients who are older than 65 years and White were less likely to report difficulty accessing services through the program, a proxy of immediate program benefits. More highly strained and stressed clients were likely to report more difficulty accessing services and supports. Clients who report higher amounts of physical strain, caring for a care recipient with dementia and reported difficulty accessing services were associated with deriving limited long-term benefits from using the program. Use of certain NFCSP services and supports were found to positively influence perceptions of difficulty accessing services as well as perceptions of long-term benefits from program use.

Chapter 6 summarizes and integrates the findings from the previous chapters and outlines the study’s limitations and strengths. This chapter also includes recommendations for future research and suggestions for additional questions on caregiver assessments and NSOAAP-CM.

# CHAPTER 2: SYSTEMATIC REVIEW OF THE UTILIZATION OF LONG-TERM CARE SUPPORT SERVICES BY FAMILY CAREGIVERS OF OLDER ADULTS (Manuscript #1)

**Key words:** Informal care, care recipient, interventions, long-term care support services, national family caregivers support program

**Potential Journal for Submission:**

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## ABSTRACT

**Purpose:** This article reviewed published literature on the use of long-term care support services (LTSS) by family caregivers of older adults, with an extensive focus on the National Family Caregiver Support Program (NFCSP). The major program components of the NFCSP are described along with previous research documenting the program's implementation and earlier studies' use of program data to profile program clients, understand the use of program services and assess the program's impact.

**Methods:** A review of the literature focused on the use of LTSS interventions that sought to alleviate the burdens often associated with caregiving of older adults, and the use and impact of NFCSP's services and supports. This literature review draws upon the disciplines of public health, psychology, geriatrics, care management and LTSS.

**Results:** Earlier research described the many needs and burdens that family caregivers face in caring for older adults including addressing complex medical needs, balancing their own needs and health, other family obligations and work responsibilities. Over the last 20 years, most the of the caregiver support literature centers around the demographic differences among family caregivers who seek support. Early research on the NFCSP examined early implementation efforts by states to expand or establish local programs. Later, research began to identify the type of family caregivers who use program, their use of specific support and the impact of the program on helping to alleviate the emotional stress and physical strain often associated with caregiving. These studies, however, used a small group of study participants in a limited geographic scope or used client survey responses from around than 10 years ago.

**Conclusion:** Family caregivers represent an important source of care for millions of older adults, enabling families to avoid costly formal care. The NFSCP is the largest and most widely available federal LTSS program to offer support directly to family caregivers through a core set of services across a multi-level network of program administrators and service providers. A much more current analysis of NFCSP clients is needed to update their demographic profile, compare dementia and non-dementia program users, and examine perceptions of the programs immediate and longer-term potential benefits.

## INTRODUCTION

Family caregivers are the primary source of long term care assistance and care coordination for older adults in the US, with between 10% and 25% of family members caring for a spouse and almost half caring for an aging parent (Spillman et al, 2014; AARP, 2015). The most recent national surveys estimate approximately 18-40 million caregivers provide between 30 and 37 billion hours of uncompensated care annually (Reinhard et al, 2015; Chari et al, 2014; Spillman et al, 2014). And, many family members must also balance their caregiving responsibilities with part-time and full-time employment outside of the home as well as caring for their own children (Spillman et al, 2014; AARP, 2015).

Family caregivers' role and responsibilities may be defined by the care recipient's ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include functional mobility, eating, bathing, personal hygiene dressing, and grooming and toileting. IADLs include transportation, housework, shopping, cooking, medication management and managing finances. Many family caregivers also perform nursing or medically-related tasks such as coordinating interactions with health systems on behalf of care recipients as well as providing tasks nurses typically perform (Spillman et al, 2014; AARP, 2015; NASEM, 2016). The intensity and type of caregiver assistance with ADLs, IADLs and nursing care can also be driven by diagnoses such as cancer and dementia, which may impose disease-specific symptoms and concerns that drive the need for specific duties and tasks for family caregivers (Kim and Schulz, 2008; Schoenmaker , Buntix , & Delepeliere, J; Spillman et al, 2014; Kasper et al, 2015).

Although many family caregivers may cope well or derive benefit from their helping role (Roth et al, 2015), other caregivers may experience physical, psychological and mental stress (NASEM, 2016). The need to support family caregivers and alleviate related stressors is critical and will continue to grow as the population ages with more complex health-related disabilities. As most older adults prefer to remain in their homes or in the community, family caregivers fill a critical role with such a movement away from costly institutionalization or other more expensive paid care (Spillman & Long, 2009; Talley and Crews, 2007; NASEM, 2016).

The National Family Caregiver Support Program (NFCSP), a federally funded program facilitating access to a network of local community-based LTSS, including respite care, information, counseling, training and supplemental resources (NFCSP website). NFCSP's services attempt to address the emotional and physical burdens that are often associated with caregiving, enabling family caregivers to provide care longer (NFCSP website). This chapter summarizes the support needs of family caregivers and the literature to date that has examined the NFCSP, including early implementation of the program at the state level and early analyses of the programs impact on caregiver burden.

## METHODS

This literature review is organized into major sections: (1) family caregivers' informational, training and service needs, (2) brief overview of federal policies and programs that support family caregivers, (3) an overview of the NFCSP and (4) early publications of the NFCSP's implementation and utilization by caregivers.

The published articles and reports included in this literature review draw upon a variety of disciplines including public health, psychology, geriatrics, care management, and LTSS. Articles were identified primarily from PubMed using terms such as “family caregiver”, “dementia caregiver”, “family caregiver interventions”, “aging support and services” and “national family caregivers support program”. A Google Scholar search using similar terms also resulted in the inclusion of related and recent reports commissioned by government agencies, such as the Department of Health and Human Services (HHS), as well as national organizations such as American Association of Retired People (AARP) and the National Academies of Science, Engineering and Medicine (NASEM). Articles published within the last 15 years were heavily relied upon with a focus on US-based policies and services to ensure the presentation and discussion of more current research and knowledge.

## FAMILY CAREGIVER’S INFORMATION, TRAINING AND SERVICES NEEDS

While most family members report positive aspects of caring for a family member or friend (Roth et al., 2009; Spillman B et al, 2014), some caregivers may feel overburdened or stressed, resulting in emotional, physical and financial strain (Spillman et al, 2014; AARP, 2015; NASEM, 2016; Wolfe et al, 2017). Certain factors can result in or even exacerbate feelings of stress or strain including caring for someone with cancer and dementia, inability or difficulty in performing medical/nursing tasks, care recipients’ limitation with one or more ADLs and IADLs, higher number of the caregiving hours, co-residing with care recipient and providing care for more than a year (Roth et al., 2009; Kim et al., 2011; Li et al., 2012; Spillman et al, 2014; AARP, 2015). Difficulty in performing caregiving tasks is strongly associated with greater evidence of strain and depression when caring for family members with multiple morbidities and dementia (Giovannetti et al., 2011) and has been linked to future nursing home admissions (Mittelman et al., 2006; Spillman & Long, 2009; Sheppard et al., 2013). Along with caregiving-related strain and stress, between 22% and 36% of family caregivers report either a high or moderate degree of financial strain as a result of providing care (Spillman et al, 2014; AARP, 2015).

As care recipients' conditions and functional limitations progress, the complexity of needs of family caregivers can also evolve (Toseland et al., 2002; Washington, et al. 2011). Initially, family caregivers may express interest in more practical information and support concerning navigating the medical and social service systems, nursing care and support tasks, assistance with insurance issues and coverage and understanding the disease processes (Yedidia & Tiedemann, 2008; Washington, et al. 2011; Silva et al, 2013; AARP, 2015). As the care recipient ages and their health declines, caregivers' needs may evolve to include more complex care circumstances such as addressing challenging behaviors, incontinence, care recipients' safety at home and end-of-life decisions (AARP, 2015; NASEM, 2016).

Caring for family members with a particular disease or condition may prompt caregivers to seek information about the disease or condition itself, specific trajectory of care needs over time associated with certain diseases, and anticipated future demands on caregiver time (to balance with work life) (Washington, et al. 2011; Silva, et al. 2013). For example, a study of family members providing care for older adults with cancer, COPD and heart failure reported further assistance was needed with specific daily tasks

(Garlo et al., 2010). Dementia caregivers have noted interests in more information about the care recipient's dementia diagnosis, home safety concerns, available mental/medical care, and available community-based resources (Black et al, 2013). Not only is individualized education and information important, individualized assistance may also be needed as to how best to process, implement and tailor specific care guidelines and resources to their current care circumstances (Washington et al. 2011; Silva et al. 2013).

From the various studies that have examined the needs of family caregivers of older adults, researchers have summarized family caregivers' preferences for both broad as well as specific services and strategies to address their evolving caregiving circumstances. These services and strategies might take the form of support groups with other family caregivers, community-based programs, respite care, chore services, home-based programs, home-delivered meals and transportation (Yedidia & Tiedemann, 2008; Casado et al., 2011; Silva et al, 2013). The primary aim of such interventions is to help to develop coping mechanisms and strategies to reduce physical and emotional strain often specifically associated with caregiving (Yedidia, M. and Tiedemann, A., 2008; AARP, 2015; McGillick and Murphy-White, 2016).

## FAMILY CAREGIVERS' UTILIZATION OF SUPPORT SERVICES

Utilization of support services varies across diverse populations of caregivers. Both African-American and Hispanic caregivers have often relied on informal networks of family and friends to supplement their care and cope with caregiving difficulties (Pinquart. & Sorensen, 2005; Dal Santo et al, 2007; Hong, 2009). In earlier studies, Hispanic caregivers were less likely to use respite care services (Dal Santo et al, 2007), however more recent studies found a higher proportion of Hispanics' use of respite care when compared to Whites (Scharlach et al., 2008; AARP, 2015). Asian-American caregivers have also reported lower levels of use of formal support compared with white caregivers even while experiencing greater levels of depression (Pinquart & Sorensen, 2005; Dal Santo et al, 2007, Scharlach et al, 2008; Hong, 2009). Asian-American caregivers whose families reported being brought closer together due to family health-related crisis were thought to feel that external support might not be needed. This might also be attributed to potential language barriers in accessing support (Scharlach et al, 2008). However, a recent national survey also highlighted the recent increase in use of support services, notably respite care, by Asian American caregivers when compared to White caregivers (21% vs. 13%) (AARP, 2015).

Multiple factors may impact utilization of health and support services by family caregivers (Table 2.1). Increased knowledge of available LTSS improves utilization, as well as living separately from the care recipient, availability of private and public transportation to assist caregivers in bringing care recipients to appointments, being on Medicaid, satisfaction with service use, higher education levels, non-aggressive behavior by care recipient and performing multiple caregiving tasks (Toseland et al., 2003; Scharlach et al, 2008 Keith, Wacker, & Collins, 2009). The odds of utilizing support by dementia caregivers increases with care recipient functional impairment and frequency of memory and behavioral problems (Robinson, Buckwalter & Reed, 2005; Scharlach et al, 2008; Beeber, Thorpe & Clipp, E., 2008). Caregivers who feel burdened and indicate that their current responsibilities have a negative impact on their health, including physical strain and emotion distress, have also been more likely to use support services (Toseland et. al., 2003; Scharlach et al, 2008).

Family caregivers' lack of awareness of the availability of services and possible benefits is a key barrier in service utilization (Casado et al., 2011; Brown et al, 2012), however multiple factors may present barriers to utilization even when the availability of services is known (Table 2.1). Cost and access to support services, potential perceptions of ineligibility for financial assistance and the amount of bureaucratic red tape involved in coordinating services present considerable barriers to utilization (Winslow, 2003). Some family members might also feel that they already know everything because of their current and/or previous caregiving experiences which could result in missed opportunities to learn about newer and more innovative services (McGillick and Murphy-White, 2016). Caregivers often express reluctance in having a stranger come into their homes (Winslow, 2003; Casado et al., 2011; McGillick and Murphy-White, 2016). Some caregivers may be unsure if the staff providing support have adequate training and expertise, fearing that the quality of support services (such as respite care) may be lacking (Winslow, 2003; Sussman, 2009; Shaw et al., 2009). Perceptions and negative feelings by family caregivers can also create self-induced barriers to seeking services such as feelings of embarrassment and fearfulness as well as feelings of guilt and shame for seeking respite through services and coping to alleviate some of the burdens and challenges associated with caregiving (Winslow, 2003; Sussman, 2009).

Family caregiving needs may vary by age group and the type of relationship to care recipient. A meta-analysis of family caregiving interventions found supports to be less beneficial for many spouses rather than children as spouses may feel already prepared for the associated strain and may have long developed their own coping strategies (Sorensen et al., 2002). Older spouses might perceive caregiving as a solitary endeavor to be performed alone and without assistance. They might also feel as if they are strong enough to manage alone and not yet need help (Robinson, Buckwalter & Reed, 2005; Robinson, Buckwalter & Reed, 2013). The information and skills taught through an intervention might be novel to the children of impaired older adults who might also require extra support due to additional family and work-related responsibilities (Sorensen et al., 2002).

A meta-analysis assessing family caregiving interventions note particular outcomes of interest when determining the effectiveness of strategies including reduced depression and burden as well as increased subjective well-being, knowledge, abilities (Sorensen et al., 2002). Strategies in earlier studies appear to be more directly and consistently impactful for knowledge and abilities for performing caregiving tasks rather than reduced burden (Sorensen et al., 2002; Robinson, Buckwalter & Reed, 2005). More recently, individually-tailored support and counseling-based interventions have been linked to positive results toward outcome measures such as reducing caregiver burden and care recipient symptoms (Brodaty and Arasaratnam, 2012).

The ability to reduce and manage emotional stress is commonly cited by family caregivers when asked about the positive benefits associated with utilizing LTSS (Yedidia & Tiedemann, 2008; AARP, 2015). Caregivers specifically mention feeling a sense of community and social support by interacting with others in similar circumstances, gaining knowledge and practical suggestions, feelings of relief and renewal, providing benefits to family members being cared for and preventing placement in an institution (Winslow, 2003; Brown et al., 2012). Meta-analyses of respite care utilization found consistent positive effects across multiple studies on caregiver depression (Lopez-Hartmann et al, 2012). Interventions and training aimed at increasing family caregivers' self-efficacy and reducing the difficulty that caregivers may have in performing health and nursing related tasks have the potential to lower strain and depression (Giovannetti et al., 2011).

When services are received early, dementia caregivers can acclimate to the care demands posed by the cognitively impaired care recipient while receiving formal assistance. Dementia caregivers who sought and utilized support services, notably in-home help, early in their caregiving careers were more likely to delay nursing home utilization (Gaugler et al, 2005). A sense of comfort, advice and emotional support is often accompanied with in-home help to new caregivers as they begin to cope with the overwhelming challenges associated with caring for a loved one (Gaugler et al, 2005). The state-wide implementation of a dementia training program that sought to increase caregiver knowledge and mastery improved competence, management of the situation, helped manage expectations, improved reactions to disruptive behaviors and reduced caregiver depression (Samia et al., 2012). When program participants were followed up to a year later, 90% agreed that the strategies that were taught continued to be useful to them (Samia et al., 2012). Dementia caregivers' use of counseling and support interventions can significantly reduce nursing home placement by almost 30% with a median delay of 1.5 years in nursing home admissions in one study (Mittelman et al, 2006).

While the previously mentioned interventions have shown positive outcomes in providing support for family caregivers, these studies have used a small group of study participants in a limited geographic scope. Over the last 20 years, the federal government has taken the findings from such research to inform the development of policies and programs to scale up LTSS for family caregivers nationally. The next section summarizes these focused federal efforts and provides early assessments of the potential impact of national programs to support family caregivers.

## FEDERAL FAMILY CAREGIVING POLICIES AND PROGRAMS

Policy, regulatory and legislative efforts following the 1991 American with Disabilities Act contributed to formalizing the shift of care for older adults away from institutionalized care to care in the home, precipitating the need for more home-based LTSS. US Supreme Court decisions impacting the Olmstead Act and Americans with Disabilities Act (ADA) pushed the federal and state governments to increase and integrate community-based services for people with disabilities, particularly older adults, reducing the need for institutionalization (ie. Nursing homes) (Fox-Grage, Coleman & Blancato, 2001; Rosenbaum, 2001).

While limited, the Centers for Medicare and Medicaid Services' (CMS) does provide some support for family caregivers of older through the Medicare and Medicaid programs. CMS grants and waivers allow state Medicaid programs to offer a range of home-based services to persons with disabilities including personal assistance with ADLs, respite care of frail elders and adult day care services, allowing family caregivers a break from their daily responsibilities (Fox-Grage, Coleman & Blancato, 2001; CMS, 2007; Doty & Spillman, 2015). More recent changes have encouraged the development of a more self-directed service delivery model of personal assistance services, enabling beneficiaries to pay a “legally liable relative” directly for personal care (CMS, 2007; Doty & Spillman, 2015). Under the Medicare hospice benefit, family members are provided training to support care recipients, inpatient care to provide respite, and grief counseling for up to a year following a family member’s death (CMS, 2007). CMS also offers supplemental training and assistance under Medicare’s home health and Medicare Durable Medical Equipment provisions (making assistive technologies accessible), (CMS, 200; Doty & Spillman, 2015). For a limited time, Medicare Advantage Plans also offer respite care (CMS, 2007). If the care recipient consents, HIPPA rules allow health care providers to disclose protected health information to enable family members to provide care more effectively (CMS, 2007).

In addition to Medicare and Medicaid, additional federal programs have been created to provide more support and resources to family caregivers. The US Department of Veterans Affairs (VA) administers the Program of Comprehensive Assistance for Family Caregivers which includes monthly travel expenses for provider visits, access to health care insurance, mental health services and counseling and caregiver training. Similar to the Medicaid and Medicare programs, the provision of the services for the family caregivers are based on the eligibility of the care recipient. Eligible Veterans include those who sustained a serious physical and mental injury in the line of duty on or after September 11, 2011 (VA).

While CMS and the VA offer support services to family caregivers through care recipients, programs offered through the Administration and Aging (AoA), within the US

Administration for Community Living (ACL), provide services and supports directly accessible by family caregivers through specifically designated programs, notably the Alzheimer's Disease Supportive Services Program (ADSSP), Lifespan Respite Care (LSP) and the National Family Caregiver Support Program (NFCSP). Created in 1992 by Congress, the ADSSP encourages states to develop models of assistance for persons with Alzheimer's and related dementias and their family caregivers. ADSSP delivers supportive services, translates evidence-based models and advances state initiatives toward coordinated systems of HBCS using proven and innovative models of care (ADSSP website). A recent program status summary reports 41 current grants in 24 states, along with the District of Columbia and Puerto Rico, annually serving just over 20,000 persons with dementia and their caregiver (~10,000 each). And in 2006, the Lifespan Respite Care Program was launched to support coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs with the goal of improving the delivery and quality of such services. As of 2012, implementation grants have been awarded to 30 states and the District of Columbia (LRCP website). The NFCSP, the largest federal program that directly services family caregivers will be discussed in more detail in the next section.

## NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Settlements reached by some state attorney generals with the tobacco industry in the late 1990s along with state legislature-appropriated general revenues created funding sources for enhanced services targeting older adults and family caregiving programs (Fox-Grage, Coleman & Blancato, 2001). States, such as California and Pennsylvania, mandated the development of new education and information programs for family caregivers, expanded adult day respite services and sought to coordinate services across various providers (Fox-Grage, Coleman & Blancato, 2001). Developed in 2000, California's Caregiver Resource Center (CRC) network sought to provide specialized information and referrals, family consultation and care planning, short-term counseling, support groups, professional training, legal and financial consultation and education for family members caring for persons with cognitive disorders (such as Alzheimer's disease, stroke, Parkinson's disease and related disorders) (CCRC website Fox-Grage, Coleman & Blancato, 2001). Pennsylvania's Caregiver Support Program (PCSP), also developed in 2000, began to offer benefits to relieve caregiving-related burden including providing a range of services and financial assistance for family caregivers of older adults (PCSP website; Fox-Grage, Coleman & Blancato, 2001).

Drawing upon the preponderance of evidence-based research at the time of legislation as to how to meet the range of family caregiving needs while also providing flexibility to states' implementation efforts, the NFCSP was established in 2000 through an authorization under the Older Americans Act (OAA) (H.R. 782, Sec. 316. 106th Cong. (2000)). Congress and AoA drew upon successful experiences and best practices from state level implementation of support services, notably California and Pennsylvania, to identify the types of service components that might populate an effective multifaceted system of support for family caregivers (AoA, 2002). The NFCSP provides grants to states based on the percentage of older adults over the age of 70 (across the overall population) to fund a range of support services that assist family and informal caregivers. Thus, the NFCSP is one of the first and most far-reaching federal programs to recognize family caregivers as the primary client and consumer rather than the care recipient, highlighting explicitly “the important role that family caregivers occupy in our nation’s long-term services and supports system” (NFCSP website; Foster & Kleinman, 2011).

The NFCSP has three broad goals in supporting family caregivers. First, provide coordinated support through the national aging network (Figure 2.1) to assist family and informal caregivers to care for their loved ones at home. Second, support caregivers dealing with the emotional, physical and financial tolls of caregiving. And third, reduce caregiver stress, depression, and anxiety to enable caregivers to continue to provide care longer, thereby avoiding or delaying the need for costly institutional care (NFCSP website). When caregivers are supported in their roles, they may be able to provide better care for longer periods of time, benefiting both their families and society as a whole (Mittelman et al, 2006; Foster & Kleinman, 2011; NASEM, 2016).

Under the original legislation, the following populations of family caregivers were eligible to receive services through the program (NFCSP website) –

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer’s disease and related disorders;
- Grandparents and other relatives (not parents) 55 years of age and older providing care to children under the age of 18; and
- Grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

Care recipients must have two or more activities of daily living (ADLs) limitations or a cognitive impairment to be eligible for certain NFCSP services (AoA, 2002).

While every family caregiver who meets the above criteria, regardless of income, can access NFCSP services, a 2006 amendment to the Older Americans Act pushed states to prioritize family caregivers who provide care for individuals (regardless of age) with Alzheimer's disease and related dementias, older relatives providing care for children with severe disabilities, older family caregivers with social and economic needs and older family caregiver caring for adults with severe disabilities (H.R 6197. Sec. 321. 109th Cong. (2006)).

### NFCSP Services and Components

AoA provides grants to State Units on Aging (SUAs) to enable Area Agencies on Aging (AAAs) within SUAs and Tribal Organizations to provide direct services or contract with local public and private services providers (LSPs) to support family caregivers through an extensive aging network (Figure 2.1). This provision of funding enables states and local communities to offer or expand the offerings of five core services (NFSCP website) including:

- **Information** to caregivers about services and supports available to them;
- **Assistance** to help caregivers gain access to supportive services and resources with an emphasis on helping older adults remain in their homes and communities;
- **Individual counseling, organization of support groups, and training** to assist caregivers in making decisions, solving problems and gaining knowledge related to their caregiving role;

- **Respite care** to temporarily relieve caregivers from their responsibilities; and
- **Supplemental services** to complement the care provided by caregivers (limited basis such as transportation and assistive devices).

These services also work in conjunction with other AoA services to provide a coordinated set of supports that caregivers can access on behalf of themselves and the older adults for whom they provide care. Each family presents their own unique circumstances, preferring particular services or combination of support to meet their needs (NFCSP website).

In 2015, with annual funding around $145 million, the NFSCP provided 1.2 million contacts to family caregivers assisting them with accessing local support services, counseled and trained over 116,000 caregivers and provided an estimated 6.3 million hours of respite care and temporary relief for 67,000 family caregivers (ACL, 2018).

### State Implementation Efforts of the NFCSP

Early research on the NFCSP examined initial efforts and challenges by states to implement or expand its diverse program components (Feinberg, Newman & Van Steenberg, C., 2002; Feinberg & Newman, 2004; Feinberg & Newman, 2006). The advent of NFCSP enabled many states to begin offering support services, expand the number of different type of services and/or increase the number of family caregivers served. Early studies found that for many states and program stakeholders, viewing family caregivers as a “consumer” or “client” represented a huge and challenging paradigm shift (Feinberg, Newman & Van Steenberg, C., 2002; Feinberg & Newman, 2006). Additional challenges included changing the mindset of stakeholders who had difficulty accepting the caregivers as the primary client, limited budgets, outreach to all caregivers especially in rural areas, reaching caregivers early, outreach to employed caregivers, handling family conflict, balancing flexibility with the need for structure and integrating efforts with other home and community-based programs (Feinberg & Newman, 2006; Link, 2016).

By around 2005, the majority of states were able to offer the full complement of NFCSP components with a small number (20%) lagging in implementing counseling services for caregivers (Feinberg &Newman, S., 2006). The leading supplemental services that states initially offered included home modifications (78%), homemaker/chore/personal care (77%), assistive technologies (77%) and transportation (69%). Most states reported one or more consumer-directed options, for example, enabling caregivers to select and facilitate funding for a respite care provider of their choice, offering a voucher or budget for supplemental services, or offering caregivers a menu of services that best fit their specific needs. Under the NFCSP, 30 states allowed direct payment to family caregivers for respite care, personal care or any other service. However, some states restricted payment to certain family members such as spouses, parents or guardians, and minor children (Feinberg &Newman, 2006).

An examination of California's implementation of the NFCSP was conducted to assess service gaps within the existing resources of their local AAAs (Whittier, Scharlach, & Dal Santo, 2005). AAAs are federally mandated to assess local needs and planning services for older adults and their caregivers, serving as an important gateway to services. Although California has an extensive array of caregiver services, many of these service providers were not identified in AAA strategic and implementation plans. The most common gap identified by the majority of the AAAs across the NFCSP components was the lack of multilingual and culturally-appropriate services and resources. The lack of available transportation was seen as a barrier to accessing services for caregivers themselves as well as care recipients. While access to respite care was available through the majority of AAA, emergency, unplanned, overnight and weekend respite was seen as a major service gap. All of these service gaps were found to be exacerbated in rural areas where the lack of health and social services can be particularly prominent.

A multivariate analysis was conducted to determine the influence of state-level policy characteristics on state-wide implementation of the NFCSP (Guinta, 2010). A secondary analysis was conducted using data from a 2003 survey of state administrators of family caregiving programs to assess implementation of the NFCSP range of services. State-level characteristics and dimensions included demographic, historical (existence of caregiver programs before NFCSP), political (Olmstead and caregiving are perceived as a priority; Democratic majority), and organizational (caregiver is the client, joint funding/coordination with other services, single point of entry, and uniform assessment). The existence of single points of entry was a predictor of higher use of information services. Results indicated that states that delivered higher counseling, support and training service units had the lowest proportions of non-White caregivers and had a caregiving program that existed prior to the NFCSP. And surprisingly, joint funding with other HCBS efforts were actually less likely to deliver higher levels of respite care services to family caregivers.

## Previous Analyses of NFCSP Client Utilization and Outcomes

The program information and studies presented in the previous section summarized the views and challenges of states as they implemented the NFCSP program. While the information is helpful in providing the perspectives of state and local administrators and charting the expansion of the program, understanding the experiences of family caregivers participating in the program are also essential. Few studies have analyzed surveys of NFCSP clients directly to describe their racial and socioeconomic background, utilization of support services and the perceived impact of these services on their caregiving circumstances. Table 3.2 summarizes these studies found in the literature followed by study descriptions that capture the perspective of NFCSP clients and the perceived impact of the program.

Two early analyses of self-reported client data (collected in 2001 and 2002) from a state's caregiver support services program were conducted to assess how well program components related with caregiver outcomes and any differences in such outcomes by gender (Chen Hedrick & Young, 2009; Chen, 2014). Using subscales from the "Caregiver Appraisal Scale (CAS)", caregivers seeking services through Seattle's AAAs were asked questions related to their 'Subjective Burden', 'Caregiving Mastery', and 'Caregiver Satisfaction' ('Impact of Caregiving' and 'Cognitive Reappraisal' subscales were not used). Most caregivers who responded to the survey were female (81.7%) while male caregivers were found to be older as they were most likely to be caring for a spouse/partner (Chen, 2014). Caregivers reported an average use of 1.9 services, with most using the program to seek information about available services (Chen, Hedrick & Young, 2009). For the survey subscale 'Subjective burden', caregivers who used counseling and education services reported lower levels of burden (Chen, Hedrick & Young, 2009), notably among male caregivers (Chen, 2014). Male caregivers also reported better outcomes especially when using respite and supplemental services (Chen, 2014). Use of financial support services was more highly associated with positive caregiving appraisals than other services used. Rather, use of respite care and supplemental services were not associated with positive caregiver appraisal or other beneficial outcomes (Chen, Hedrick & Young, 2009), especially among female caregivers whose use of respite care was associated with perceptions of lower caregiver mastery and caregiver satisfaction (Chen, 2014). Researchers attribute this to the high level of stress among these selected caregivers (Chen, Hedrick & Young, 2009).

Foster and Kleinman (2011) authored a research brief using responses from the 2009 National Survey of Older American Act Participants – Caregiver Module (NSOAAP-CM) to describe the demographic characteristics of program clients that were served, the type and amount of care the clients provide, the services they receive and the benefits they report through the use of NFSCP services. NFCSP clients were found to be were mostly adult women caring for a parent. Spousal caregivers were older and less educated with lower income. They also reported fair or poor health. More than two-thirds of NFCSP clients (68%) were found to be greater than 60 years of age and cared for a family member aged 85 and older. Approximately 59% of NFCSP client reported caring for someone with Alzheimer’s disease or dementia and 67% cared for someone with at least three limitations in ADLs. About 70% of clients reported providing at least 40 hours of care per week. Emotional strain was the most commonly reported type of strain affecting twice as many spouses and adult children compared with other clients.

Fourty-four percent of spouses reported physical strain and 33% reported financial burdens as a result of caregiving. The majority of clients received information (80%) through the NFCSP, followed by supplemental services (~60%), respite care (~50%) and training and education (~30%). NFCSP clients reported that they derived positive benefits from the program. The majority of clients reported that because of services received through the NFCSP, they were able to provide care longer, reported feeling less stress and reported that services helped them deal with the difficulties of caregiving.

Also using responses from the 2009 NSOAAP-CM, Herrera et al. (2013) developed a racial profile of the clients who utilized NFCSP services, and assessed the impact of the services on care recipients' ability to continue to live independently at home. White clients represented a large majority of the respondents (80.7%) followed by African American (13.8%) and Hispanic clients (5.5%). Hispanic and African American caregivers were more likely to be younger (<64 years old), report lower incomes (less than $20,000) and to be female when compared to White clients. Older adults being cared for by African American and Hispanic clients were more disabled including more likely to report limitations in 3+ ADLs and have higher proportions of hypertension, high cholesterol, diabetes and kidney disease. Hispanic clients were more likely to access support services from community-based agencies rather than the AAAs, while African American clients were more likely to seek services from AAAs. White clients were more likely to provide additional paid caregiving and rely on additional family and friends. Whites (57.1%) and Hispanics (45.8%) were most likely to report that their care recipient would not be able to remain at the same address if caregiver support services became unavailable. Hispanic clients also reported a higher proportion of unmet respite care needs.

To assess whether NFCSP services were reaching the most vulnerable caregivers, the demographic characteristics of clients and care recipients included in the study were compared with the national profile of older adults captured in the Hispanic Established Populations for Epidemiologic Study of the Elderly (H-EPESE) and the Health Retirement Survey (HRS) (Herrara et al, 2013). Based on most risk factors associated with institutionalization such as disability, Medicaid coverage and living alone, a comparison of NFCSP data with these national surveys of older adults found considerable utilization of services from a vulnerable population. This comparison also found that NFCSP services reached the caregivers of more highly educated minority seniors. Hispanic and African American clients had higher levels of education with increased proportions of high school graduation among NFCSP users compared with minority family caregivers capture in national surveys.

### Recent evaluation of the NFCSP Program

A recent process evaluation of the NFCSP was conducted by AoA to assess the perspective of SUAs, AAAs and LSPs (Lewin, 2016). The survey found that funding through NFCSP enabled states to considerably expand their offerings of services and supports to family caregivers. The majority of local AAAs have been able to offer NFCSP’s set of core services, with respite care identified as the most requested service by program clients. The majority states and AAAs make a specific effort to prioritize and serve caregivers of persons with Alzheimer’s disease or dementia. Over half of the states reported using a standardized process for assessing caregiver needs. Unfortunately, over the last few years, state and local program administrators have experienced increased demand and caseloads while also reporting limitations in funding, availability of services and staffing shortages at the AAA level (Lewin, 2016).

## CONCLUSION

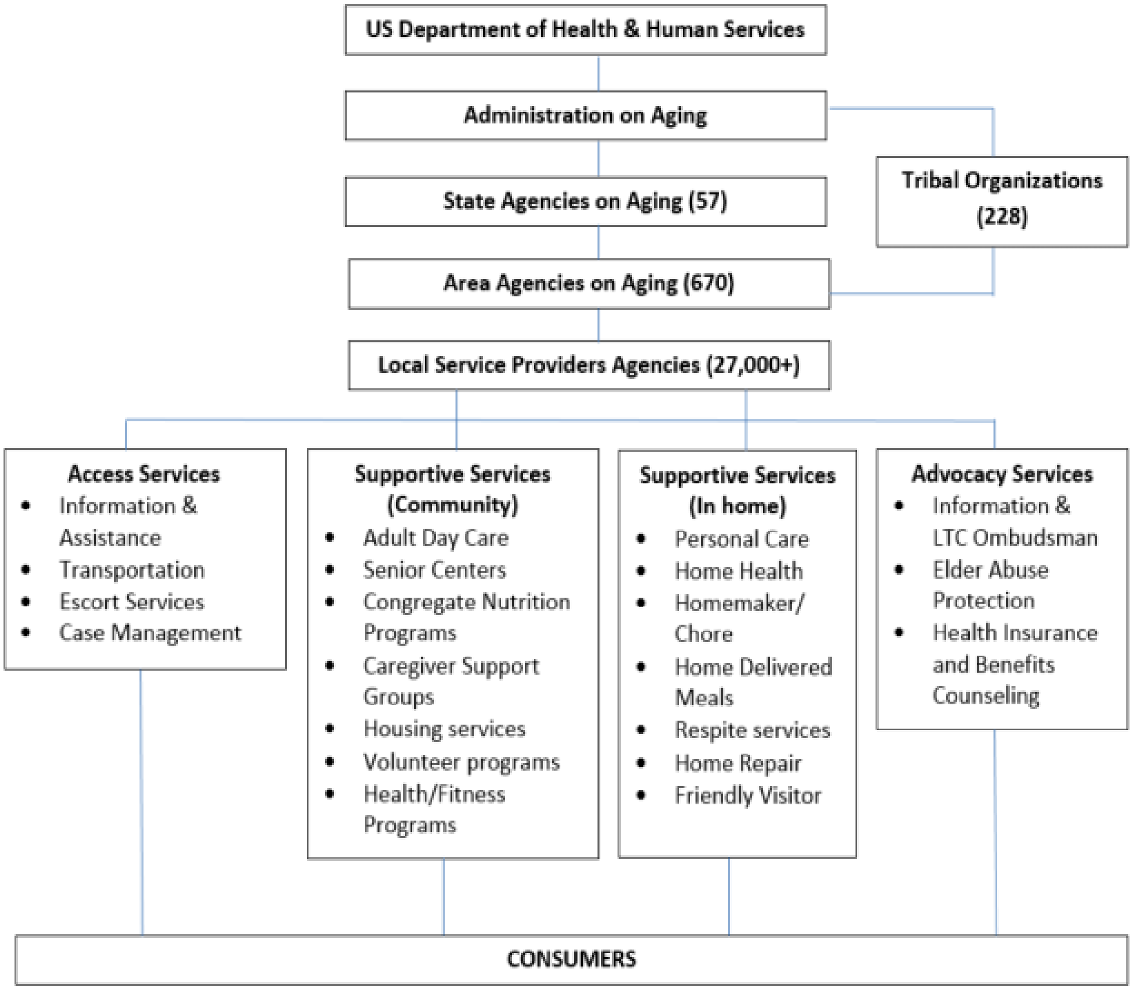
Family caregivers represent an important source of long term care for millions of older adults, enabling families to avoid costly formal care. For many caregivers, the role and weight of responsibility of providing care can lead to feelings of burden, emotional stress and physical strain. To support family caregivers and enable them to provide care longer, a variety of LTSS have developed and made available over time to offer information, training and respite. Utilization of these services by family caregivers may evolve as the complexity of the needs changes as their family members age or their health declines.

The NFSCP is the largest federal program to offer support directly to family caregivers through a core set of services across a multi-level networks of service providers. While the program is over 15 years old, a search of the published literature and a review of government reports have yielded only a limited number of articles assessing the implementation of NFCSP services at the client level. Earlier reports summarized experiences at the state level as the program was launched and expanded. Previous analyses of NFCSP client data only assessed utilization and impact of services based on a small geographical area and using responses from a much earlier survey of program clients. A much more current analysis of NFCSP clients is needed to update the program’s demographic profile, summarize the health status of both caregivers and care recipients, and examine perceptions of the programs immediate and longer-term potential benefits.

**Table 2.1. Selected factors that may increase or decrease utilization family caregivers' of older adults use of LTSS**

| Increase utilization of services | Decrease utilization of services |
|---|---|
| • Knowledge about the service<br>• Caregiver living separately from the care recipient (except for potential cases of dementia)<br>• Availability of private and public transportation to assist caregivers in bringing care recipients to appointments<br>• Care recipient's use of Medicaid<br>• Satisfaction with service use<br>• Higher education levels<br>• Non-aggressive behavior by care recipient<br>• Caregiver performing multiple care-related tasks<br>• Caregivers who feel burdened by their responsibilities<br>• Caregivers who perceive caregiving as having a negative impact on their health<br>• Feeling a sense of community and support | • Lack of awareness of the availability of services and potential benefits<br>• Reluctance concerning strangers coming into the home<br>• Caregivers feel they already feel comfortable with responsibility and duties<br>• Difficulty in accessing services<br>• Overwhelmed by the overall level of services needed<br>• Feelings of embarrassment and fearfulness<br>• Feeling as that caregiving should be a solitary endeavor and fits spousal role<br>• Concerns over costs and financial ineligibility, when seeking services |

**Figure 2.1. National Aging Network (2002)**



Source: The National Association of State Units on Aging

**Table 2.2. List of previously published studies directly assessing family caregivers who NFCSP support services**

| Authors and Year | Publication Title | Study Sample Size and Geographic Location | Survey Instrument or Data Source | Study Purpose and Measures of Interest | Study Results and Findings |
|---|---|---|---|---|---|
| Chen, Hedrick & Young, 2009 | A pilot evaluation of the Family Caregiver Support Program | n=164<br>Seattle | Surveys using the Caregiver Appraisal Scale (Lawton & Brody, 1969) was sent to clients between 2001 and 2003 | Study Purpose - Link type of caregiver support service with caregiver outcome<br>Six measures – caregiving appraisal scale, caregiving burden, caregiving mastery, caregiving satisfaction, hour of care, and service satisfaction | ○ Clients who received counseling and education services reported lower levels of burden<br>○ Use of financial assistance was most associated with more positive caregiver appraisals than any other service<br>○ Use of respite and supplemental services were not associated with any positive caregiver appraisals |
| Chen, 2014 | Differences in Outcomes of Caregiver Support Services for Male and | n=148[1]<br>Seattle | Surveys using the Caregiver Appraisal Scale (Lawton & Brody, 1969) was sent to | Follow-up study to the first study.<br>Study Purpose – Determine whether | ○ Overall, male clients perceived less subjective burden than female clients especially when using respite care and supplemental services |

| | | | | | |
|---|---|---|---|---|---|
| | Female Caregivers | | clients between 2001 and 2003 | different types of caregiver support services are associated with differences in caregiver outcomes for male versus female clients.<br>Same measures are used except for hours of care. | o No difference in outcomes between the sexes when counseling and education services are used<br>o For female clients who only used financial support, more positive caregiver appraisals were found along with greater mastery and caregiver satisfaction |
| Foster & Kleinman, 2011 | Supporting Family Caregivers through Title III of the OAA | n=1793 | 5th Annual National Survey of OAA Participants – Caregiver Module (NSOAAP-CM) (2009) | Program data bulletin commissioned by the Administration on Aging to describe NFCSP clients who help frail older relatives.<br>The bulletin describes the types and amount of care the clients provide, the services caregivers receive from the NFCSP, and the | o Most NFCSP clients were daughters caring for a parent<br>o More than two-thirds of caregivers were aged 60 and older caring for a family member aged 85 and older<br>o Most NFCSP clients were caring for care recipients with dementia and some had at least 3 ADL limitations<br>o Emotional strain was the most commonly type of strain reported by NFCSP clients |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  |  |  |  | benefits they report deriving from NFCSP services. Data were examined separately for spouses, adult children, and other clients. | o Most NFCSP clients used the program for information and supplemental services |
| Herrera et al., 2013 | Variation in Older American Act Caregiver Service Use, Unmet Hours of Care, and Independence Among Hispanics, African Americans, and Whites | N=1749[2] | 5th Annual National Survey of OAA Participants – Caregiver Module (2009) | This study (1) examines the racial composition of NFCSP clients, (2) determines the relationship between service use and care recipient's ability to live independently at home and (3) compares the demographic NFCSP client profile with other similar national cohorts of minority family caregivers. | o NFCSP clients were most likely to be older, white and female<br>o Minority caregivers reported caring for a family member with more ADL limitations<br>o White caregivers were more likely to be able to supplement NFCSP services with additional paid caregiving<br>o White and Hispanic caregivers were most likely to report that the care recipient would not be able to remain at the same address without NFCSP services<br>o Compared with other survey cohorts, Hispanic and African American caregivers who are |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | NFCSP clients were more educated |

[1] Sixteen (16) surveys did not specify gender and were eliminated from the follow-up analysis (Chen Y., 2014)

[2] Herrera et al, 2013 only included Hispanic, African American and White family caregivers

# CHAPTER 3: RESEARCH DESIGN AND METHODS

This chapter describes the methods that were employed in Chapters 4 and 5. This Chapter is organized into the following sections: (1) conceptual framework; (2) data sources; (3) study design and sample populations; (4) measurement; (5) missing data; and (6) analytic approaches. When appropriate, each section will indicate when data and methods vary by Chapters 4 and 5.

## 3.1 Conceptual Framework

This study aims to develop a profile of National Family Caregiver Support Program (NFCSP) users using the most recent program data (2016) by summarizing clients' demographic and health characteristics, caregiving circumstances, service utilization and perceived program benefits, stratified by care recipients' dementia status (Chapter 4) and assess which clients may be more or likely to derive immediate and long-term benefits from using the program (Chapter 5). Chapter 4 also compared selected survey responses from recent NFCSP clients (2016) with responses from an earlier survey (2008) to assess any differences in the percentage of dementia caregivers and client utilization of specific services. To organize and illustrate the relationship among NFCSP client characteristics, service use and perceived program benefits, this chapter describes the conceptual framework that was used to inform the development of specific research aims and accompanying analytic methods.

### *3.1.A Application of an Family Caregiving Intervention Organizing Framework*

In 2011, Van Houtven, Voils and Weinberger published a framework to articulate the process by which aspects of caregiving activities and outcomes appear to be impacted by the utilization of intervention or support services. The authors based the development of specific constructs within their framework on a systematic review of published literature using search criteria that focused on the demographic characteristics of caregivers and care recipients, specific activities that caregivers engage in to provide care for their family members, the types of support that family caregivers seek to ease their burden and any outcomes resulting from utilization of support services, interventions and coping strategies.

Figure 3.1 presents the caregiving organizing framework along with its four critical constructs including: (1) caregiver and care recipient demographic characteristics which may affect the utilization of interventions, (2) utilization of interventions and potential immediate impacts of use on circumstances of caregiving, and potential longer-term outcomes related to intervention use for the (3) caregiver and (4) care recipient including their psychological and physical health, further utilization of other health and long-term care services and economic status  (Van Houtven et al, 2001). Identification and mapping of NFCSP client data to these specific constructs helps to describe the characteristics of family caregivers who utilize the program’s services (Chapter 4) and assess how these characteristics may differ in the program’s ability to achieve immediate and long-term goals (Chapter 5).

The first construct of the framework describes family caregiver and care recipient baseline characteristics, which can inform what type of caregivers who seek support, their selection of interventions or services and their response to intervention strategies. Using NFCSP program data, Chapter 4 profiles client and care recipient demographic information such as age, socioeconomic status, education, and the relationship between the caregiver and care recipient. Health status for both the caregiver and care recipient is also relevant, including diagnosed diseases and conditions as well as any cognitive or physical limitations. Specifically, care recipients' disease and conditions can guide expectations for families around the likely duration of the caregiving episode and circumstances, affecting important perceptions around whether support is needed and the type of information or service that should be sought through the NFCSP (van Houtven et al., 2011).

The second construct of the framework includes caregiving activities that may be immediately impacted after exposure to a caregiving intervention, such as seeking services through NFCSP. Some of these immediate impacts may include the ability to access needed services, the actual use of specific services, enhancement of clinical skills and knowledge, psychological skills and quantity of care provided or the time spent caregiving, reflecting opportunity cost of a caregiver's time (and perhaps the cost-effectiveness of the intervention). Using the client and care recipient characteristics included in Construct 1 and summarized in Chapter 4, the focus of the Chapter 5 will explore how characteristics of clients may vary in deriving limited immediate benefits from use of the program, particularly reporting difficulty accessing services. The framework's authors note that an intervention's impact may go no further than affecting caregiving activities, such as reducing responsibilities and immediate burden, without any further impact on longer term outcomes (Van Houtven, et al, 2011).

The third construct of the organizing framework outlines the first of two sets of potential long-term outcomes that caregiver interventions seek to impact longer term (Van Houtven, et al, 2011). For caregivers, there are positive (such as role satisfaction) and negative (such as depression and stress) outcomes that can be classified into four categories: psychological health, physical health, utilization and economic status. The fourth construct of the organizing framework encompasses more distal or longer-term outcomes that are potentially impacted by caregiver intervention for the care recipient or family member (van Houtven, et al, 2011). Together, these constructs infer the caregiving interventions' role in potentially improving or maintaining caregiver's emotional stress, physical strain and financial status, perhaps reducing or preventing the use of institutionalized care such as hospitalization and nursing homes (van Houtven, et al, 2011). NFCSP program data includes a series of questions that attempts to assess longer-term outcomes or benefits based on client's use of the program such as reducing stress and enabling them to provide care longer (reducing the need for institutionalization) as well as whether the program benefits the care recipients.

### 3.2 Data Sources

ACL and AoA annually examines program performance and clients' assessment of service quality across major programs and services funded under the Title III of Older Americans Act using the National Surveys of Older Americans Act Participants (NSOAAP). Among the program users who are surveyed, responses from clients who sought services through NFCSP are included through a separate caregiver module (NSOAAP-CM). Surveys are conducted via telephone and included questions about client and care recipient demographic characteristics, caregiving tasks and responsibilities impact of caregiving on the client, care recipient's diagnosed diseases and conditions, clients' use of services and supports, and perceived impact on the caregiver and care recipient. NFCSP clients are also asked questions covering the following areas: care provided, burdens associated caregiving, impact on employment, health of caregiver, demographics, health and physical functioning of care recipient, and service information and needs (https://agid.acl.gov/DataFiles/Documents/NPS/SurveyInstrument2016.pdf).

The sample selection for both the 2008 and 2016 NSOAAP-CM surveys occurred through a two-stage sampling process as part of a larger client assessment of major services implemented through Areas Agencies on Aging (AAAs). These major services include Home Delivered Meals, Homemaker, Transportation, Caregiver Service, Congregate Meals and Case Management (AoA, 2008; AoA, 2016). The first stage includes a stratified sample of 300+ AAAs (allowing for a 20% non-response rate) within a sampling frame of 600+ agencies based on AAA agency size and number of people served. The AAAs sampled were selected independently within five budget-size strata, based on the square root of the total budgets sizes of the AAAs. AAAs and client samples were proportionally allocated to the total of the square root of the budget sizes within each stratum. Within each stratum, the sample of AAAs was selected with equal probability, then sorted by Census region. The sample of AAAs was further sorted within region by the measure of size variable, which is the square root of the budge size for the given AAA. This method was preferred over using direct proportional to size (PPS) sampling because earlier national surveys found that budget size was not necessarily well correlated with the total number of clients in each agency for each service. While budget size was still used as part of the sample selection, the square root of the budget size reduced the effect of large variation in budget sizes among the AAAs (AoA, 2008; AoA, 2016).

The largest AAAs (based on budget) were selected with certainty for both 2008 and 2016 surveys, while the remaining AAAs were selected independently within each of the remaining non-certainty strata (AoA, 2008; AoA, 2016). The four regional Census Regions (Northeast, Midwest, South and West) were used as stratification variables in the selection process, with further within region stratification using MOS16 for the 2016 survey (AoA, 2016). For the 2008 survey, variables were also stratified by Census Division and state resulting in the number of agencies in each Division or state selected roughly in proportion to the total of the square root of budget of a Division or a state (AoA, 2008). Between the two time periods, the number of AAAs included in the sample increased from 310 to 316.

Client samples were drawn randomly within each sampled by AAA service type (which include Caregiver Service) (AoA, 2008; AoA, 2016). The total number of clients who receive each service within an AAA was obtained by contacting either the sampled agencies or State Units on Aging (SUAs). Clients were then randomly selected by using a software application to enable the overall probability of selection for each a client within each AAA to equal roughly the same for all clients within each sample stratum. For the AAAs in the certainty strata, the number of clients selected in each agency varied depending on the budget size of the agencies. In the non-certainty agencies, fixed-size client samples were selected from each agency for each service (AoA, 2008; AoA, 2016).

Weighting of 2008 and 2016 client data included four steps (AoA, 2008; AoA, 2016). First, base weights, the inverse of the overall selection probability of a client, was obtained by calculating the base weight for an agency and multiplying that weight by the within-agency-level based weight of a client in a service within that agency. Second, the base weights were adjusted for non-responses at the agency-level and client-level. Nonresponse adjustments were applied specific to each service group within cells defined by Agency size and Census region. Third, extreme weights were trimmed to the keep the variance of the survey estimates within an acceptable level. Upper acceptable limits were determined by using the median base weight within a service group. And fourth, a post-stratification adjustment for the weights for the 2016 survey was conducted at the regional level to benchmark the estimated number of clients in a service (based on the trimmed, nonresponse-adjusted weights) to the known number of clients (control total) obtained from AoA's State Program Reports (SPR) (AoA, 2016). For 2008, a post-stratification adjustment was made for specifically for caregiver services (AoA, 2008). Caregiver clients were categorized by three groups according to which service was received – respite care, counseling and supplemental services. A separate set of post-stratified weights was created for each of these three subgroups to be applied to those receiving that particular service. Weighted totals were forced to equal the total number of clients receiving respite, counseling and supplemental services, respectively.

### 3.3 Study Design and Sample Population

This study used cross sectional secondary data captured from the NFCSP clients who responded to the NSOAAP-CM in 2008 and 2016. Only a limited number of previous studies were found to use responses from NSOAAP-CM for developing similar descriptions of NFCSP clients, with the most recent national profiles published from the summary and analyses using 2009 survey responses (Foster, L and Kleinman, R., 2011 and Herrara et al., 2013). Chapter 4 sought to update the literature by summarizing and analyzing 2016 client data with additional comparisons conducted between dementia and non-dementia caregivers and selected responses from 2008 clients who used the program.

While predominantly known for providing direct support for family caregivers of older adults (60 years and older), the NFCSP does provide support for a very small number of older adults, such as grandparents, who may care for young children (up to 18 years) and parents caring for adults with disabilities (18-59 years). As the focus of this study is on family caregivers caring for older adults, the primary exclusion criteria for the data analyzed in Chapters 4 and 5 will be the non-inclusion of NFCSP clients who were self-identified as a parent or grandparent.

This study is subject to a number of data constraints. First, baseline data was not available to describe family caregiver experiences prior to accessing services or assistance through the program. Second, the study did not use a control group of caregivers who have not sought support services through NFCSP as a basis of comparison. Third, not all care recipients may have received an accurate or timely diagnosis of dementia, so there might be an underestimation of the number or percentage of dementia caregivers the program serves. Fourth, not all family caregivers are aware of and may not have access to the NFCSP program and therefore, results from this study may not be generalizable to the larger family caregiving population. And finally, the difference in the strategies used to develop of the 2008 and 2016 sample populations may result in findings that might not accurately reflect true differences between the two time periods.

### *3.3.A Study Design and Sample Population – Chapter 4 and 5*

Approximately, 1,709 clients were included in the final sample of responses for the 2016 national survey. However, this study excludes parents and grandparents, so a final sample of 1,651 clients was used. Table 3.1 presents a table of unweighted responses from the 2016 NSOAAP-CM summarized by NFCSP clients demographic and health characteristics, caregiving circumstances utilization of individual NFCSP services and reported program benefits. For the 2008 survey, 1,629 total client responses were originally included in the final sample. Table 3.2 presents a table summarizing selected unweighted data related to NFCSP clients from the earlier survey after excluding parents and grandparents. The number of responses that were analyzed for 2008 NFCSP client totaled 1,623.

## 3.4 Measurement

The following section summarizes the measures that were analyzed in Chapters 4 and 5 (Table 3.3). These variables reflect measures that have been cited in the published literature in Chapter 2 as well as outlined in the van Houtven et al. organizing framework (2011) as important in their potential influence concerning who seeks NFCSP assistance, the care circumstances that NFCSP clients experience and how both NFCSP clients and their family members may benefit from the services that are sought. Most of the measures were summarized and employed in both chapters.

### *NFCSP Clients and Care Recipient Characteristics*

NFCSP clients and recipient characteristics included demographic characteristics such as age, sex, race, marital status, education level, geographic location, annual income, and employment. Clients' relationship to the care recipient is summarized using item responses including 'Daughter', 'Wife', 'Husband', 'Son' and 'Other'.

Some demographic and health characteristics of care recipients were assessed, including: age, gender and the type of external financial assistance received ('Food Stamps', 'Medicaid', and 'Housing Assistance'). Health-related variables include the care recipient's health status ('Excellent' to 'Poor') and dichotomous responses ('Yes' or 'No') reported by the caregiver as to whether the care recipient received a diagnosis of Alzheimer's disease/dementia.

NFCSP clients' overall health was measured using a likert scale ('Excellent' to Poor). For Chapter 5, this measure was dichotomized ("Excellent-Good" to "Fair to Poor"). The presence of a current disability or physical condition was captured using a dichotomous measure ('Yes' or 'No), with a follow-up question ('Yes' or 'No) for clients who responded 'Yes' concerning whether their caregiving circumstance contributed to the current disability or physical condition. The amount physical strain, emotional stress and financial hardship clients associate with their caregiving circumstances were measured using a likert scale ('No/little amount ___ ', 'Moderate amount of___' and 'A lot/Very high amount ___'). For Chapter 5, measurements of physical strain, emotional stress and financial hardship were dichotomized ('No/little/moderate amount of___' to 'A lot/Very high amount ___').

### *Caregiving Circumstances*

Caregiving circumstances were measured using a variety of variables to describe their role and responsibilities. Using dichotomous responses (‘Yes’ or ‘No’), Chapter 4 included NCFSP clients’ tasks including ‘helping with dressing, eating and getting to the bathroom’, ‘help with medical needs’, ‘health with financial matters’, ‘help with preparing meals, doing laundry or cleaning house,’ ‘help with going to doctor’s appointments or shopping’, and ‘help with arranging care or services provided by others.’ And, the number of persons in addition to their older family member in which they were providing care was summarized using a dichotomous response (‘0’ or ‘1 or more’).

Caregivers were asked the number of hours of care they provide per day (‘0-10 hours’, ’11-23 hours’, and ’24 hours’) as well as how long they’ve provided care for their family member (‘less than 2 years’, ‘2 to 5 years’, and ‘more than 5 years’). For Chapter 5, both number of hours proving care (‘Less than 10 hours’ or ‘More than 10 hours’) and length of care (‘Less than 5 years’ or ‘More than 5 years’) were dichotomized. Using likert scales, additional variables used to describe NFCSP clients’ caregiving circumstances included distance between caregiver and care recipient (‘same house’ to ‘more than 2 hours away’), ability of the care recipient to be home alone (‘Can be left along all day’ to ‘Needs someone all/nearly all the time’). Ability of the care recipient to be home alone was also dichotomized for the analyses included in Chapter 5.

### *Utilization of the NFCSP Services*

Utilization of NFCSP services by family caregivers was measured with dichotomous responses (‘Yes’ or ‘No). NFCSP were asked their use of each of the core services and supports -- Respite Care, Assistance/Information, Training/Education/Counseling, and Supplemental services. Under Respite Care, NFCSP clients were further assessed whether they used ‘In-home respite’ and/or ‘Adult Day Care.’ The utilization of supplemental services included ‘home modifications’, ‘nutritional supplements’, ‘walkers/canes/crutches’, ‘specialized medical equipment’ and ‘money or stipend.’ NFCSP clients are also asked where they heard about the program. Chapter 4 summarized responses which included ‘family’, ‘friends’, ‘physician’, ‘community organization’, ‘media’, ‘social/case worker’, and ‘state office on aging’.

### *Perceived Benefits from NFCSP Service Use*

Several questions assessed NFCSP client perceptions of benefits from utilization of program supports and services using dichotomous responses (‘Yes’ or ‘No’). Perceived benefits included ‘more time for personal activities’, ‘feel less stress’, ‘easier to care for recipient’, ‘difficult to access services’, ‘know more about the care-recipient’s condition/illness’ and ‘help with caregiving-related difficulties’. Other questions assessed if care recipients benefitted from services and if utilization of services enabled NFCSP clients to ‘provide care longer’ and ‘enable care recipient to remain in the home’. In Chapter 4, these outcomes are summarized and stratified by the dementia status of care-recipients. For Chapter 5, difficulty accessing services is used as the primary outcome with the remaining questions capturing program benefits included in a principal component analysis (PCA) that is explained later in this chapter.

## 3.5. Missing Data

Tables 3.1 and 3.2 include item non-responses from 2008 and 2016 NFCSP client’s unweighted data. Item non-response was generally low (<1%) for many variables related to demographic and health characteristics of NFCSP clients and care recipients, caregiver circumstances and utilization of services from both 2008 and 2016 surveys. For variables with item non-responses less than 5%, missing values were re-categorized to the modal value. A few examples of such variables included ‘caregiver gender’, ‘home location’, ‘3+ ADL limitations’, ‘number of hours of help the caregiver provides per day’, ‘level of financial hardship associated with caregiver’ and utilizing ‘assistance/information to connect to available services’.

The item non-response for ‘annual income’ rated the highest percentage of missing data in both years (over 15%). Because of the large number of missingness and refused responses associated with this variable, ‘annual income’ was excluded from the summary of NFCSP clients (Chapter 4) and as a possible co-variate or independent variable in further analysis of perceived program outcomes (Chapter 5). Table 3.4 stratifies NFCSP client income across demographic characteristics.

## 3.6 Analytic Approach

STATA version 12 was used to conduct statistical analysis of 2016 and 2008 NSOAAP-CM survey data. The SVY command and survey replicate weights were used at the outset to account for the survey’s multi-stage sample design. A version of balanced repeated replication (BRR) called Fay’s method was further specified in STATA’s SVY command statement to calculate the sampling variances of survey estimate variances greater precision (Fay’s factor for NSOAAP = .30) (AoA, 2008; AoA, 2016).

### *3.6.A Analytic Approach – Chapter 4*

One of the objectives of this study is to develop a profile of the family caregivers and care recipients who utilize NFCSP supports and services using the 2016 NSOAAP-CM. This profile used descriptive statistics to summarize key variables that included demographic and health characteristics of NFCSP clients and care recipients, the type and length of the care provided by NFCSP clients, their utilization of specific type of NFCSP services, and perceived program benefits. From this initial profile, two comparisons were conducted. First, client characteristics for dementia caregivers who use NFCSP were compared with non-dementia caregivers. The following null hypothesis was tested –

HA$1_0$: There is no difference between dementia and non-dementia caregivers who received NFCSP supports and services.

To test this hypothesis, a series of Chi-square ($X^2$) tests were used to compare estimated proportions of primarily dichotomous and some categorical responses based on the assumption that two populations within the study are independent. The associated $X^2$ test statistics and associated p-values ($p < .05$ level) were evaluated to determine whether any differences seen between non-dementia and dementia caregivers were statistically significant enough to reject the null hypothesis.

A second analysis compared NFCSP client responses from 2008 and 2016 NSOAAP-CM. Chapter 2 noted that a stagnant budget over the last few years may have resulted in a decrease in the number of family caregivers served by the NFCSP. Also, with the 2006 amendment to the Older Americans Act, Congress pushed states to prioritize certain sub-groups of caregivers whom they felt had higher levels of burden and responsibilities including those caring for older family members with dementia and low-income caregivers. As the 2008 survey was the first collection of data after passage of the 2006 amendment and is identical to the most recent version of the current survey instrument, comparing differences between NFCSP clients in 2008 and 2016 provided an opportunity to assess if or how selected client characteristics may have changed between the two time periods. The following null hypothesis was tested –

HA$2_0$: There is no difference between the NFCSP clients who responded in the 2008 and 2016 OAA survey – Caregivers Modules

To test this hypothesis, a comparison of estimated proportions associated with variables capturing NFCSP client demographic and health characteristics, care recipient's dementia status, caregiving duties and utilization of the core services were compared using a series $X^2$ tests. Similar to the earlier comparison, STATA version 12 was used to assess any statistically significant differences ($p < .05$ level) between the groups of NFCSP clients. While $X^2$ test may indicate that there may be a relationship or difference between two variables, a major limitation when using it to test $HA1_0$ and $HA2_0$ was the inability to demonstrate strength or direction of the difference.

### *3.5.B Analytic Approach – Chapter 5*

Proximal Outcome - The primary purpose of the analyses included in Chapter 5 was to explore whether characteristics differ among NFCSP clients who reported difficulty accessing services based on responses from the 2016 NSOAAP-CM survey. Difficulty accessing services was selected as an outcome of interest because it serves as an important indicator of program performance and can infer potential gaps in the coverage of services. This variable also serves as a proxy of immediate program outcomes or benefits. Exploratory data analysis also found that clients who report difficulty accessing services were also significantly associated with other immediate and long-term program outcomes (Table 3.5). The following null hypothesis was tested –

$HB1_0$: Characteristics do not differ between NFCSP clients who report and who do not report difficulty accessing services.

This hypothesis was tested in two ways. First, a series of $X^2$ tests were used to compare NFCSP clients who reported difficulty accessing services across dichotomous and categorical data capturing client demographic and health characteristics, care recipient characteristics, care circumstances, and use of program services. The associated $X^2$ test statistics and associated p-values ($p < .05$ level) were evaluated to determine any significant variation among client characteristics in reporting difficulty accessing services.

To further validate the findings from the series of $X^2$ and further estimate the influence of client characteristics on difficulty accessing services, logistic regression was conducted (Table 3.6). First, a series of simple logistic regressions were conducted to estimate the individual odds ratios for each client characteristic on reporting difficulty accessing services. Multiple logistic regression was conducted to assess whether each of these characteristics within a full model changed when controlling for other co-variates. Multiple logistic regression was also used to explore changes in a reduced model that included only the co-variates that were statistically associated with difficulty accessing services ($p<.20$). A likelihood ratio test (LRT) was conducted to determine if any difference existed between the full and reduced models in assessing goodness-of-fit, specifically whether constraining a limited number of variables in the reduced model made a difference in the interpretation and significance of results from the full model. Results from the LRT found no difference between the full and reduced models ($p=.20$). After taking into account the NSOAAP-CM survey sampling design, an F-adjusted Hosmer-Lemeshow test (Archer and Lemeshow, 2006) found that the full model suggested no evidence of lack of fit ($p=.34$) between the expected and observed models.

<u>Distal Outcome</u> - While the program overall is perceived very positively, a deeper assessment was needed to further determine whether the program is meeting the needs of all clients and which caregivers may or may not be fully benefiting from the program long-term. The 2016 NSOAAP-CM survey includes a set of 10 questions that assess

whether and how the program has affected NFCSP clients and care recipients using dichotomous (yes/no) responses.  These 10 questions attempt to measure both immediate (Construct 2) and long-term program outcomes (Constructs 3 and 4). Principal component analysis (PCA) was performed for the purposes of data reduction and to examine the possibility of constructing one or more composite measures that credibly map NFCSP program data to constructs from the organizing caregiving framework. First, three components were identified based on factor loadings and Eigenvalues greater than 1.0 (Kaiser's criterion), which explained 50.2% of the variance (Table 3.7). Once the initial three (3) components were identified, the 'rotate' command in STATA was used with a specification of 'varimax', which assumed that the components are independent from one another. Rotating components around an X-Y axis allows for a clearer understanding and sharper pattern between the variables and components by spreading variability more evenly among the three (3) components. Component 1 loaded five questions related to NFCSP's ability to potentially improve the physical and mental health of clients and care recipients in the longer term (Table 3.8). Component 2 loaded three questions related to the ability of the client to understand more about their care recipient's illness, understand how to get services and whether the information provided through the program was helpful. The remaining two questions loaded onto Component 3, seeming to be related to maintaining the current care arrangement by loading questions that sought to measure whether the program enables the care recipient to remain in their current residence and the client to provide care longer. Among the three components, the five questions that comprised Component 1 demonstrated far higher internal consistency as compared with Components 2 and 3 (KR-20 $\alpha$= .66, .39 and .40 respectively).

The higher measure of internal consistency and higher factor loadings informed the development of a summary measure based on the questions that loaded onto Component 1. Encompassing factors central to clients' perceived long-term benefits from the NFCSP for both themselves and their care recipient(s) (Construct 3 and 4 respectively), an outcome summary measure of 'limited long-term benefit' was constructed by summing the 'Yes' responses from the 5 questions which loaded on to Component 1. This resulted in an index ranging from 0 to 5 where higher values indicated greater benefit from NFCSP services. To delineate clients who derived more or limited benefit, a dichotomous measure was developed with a cut point approximating the lowest quintile (0-2). Using this criterion, approximately 15.8% NFCSP clients reported deriving limited long-term benefits for themselves or their care recipients (Table 3.7).

A second analysis was conducted in Chapter 5 which explored whether client characteristics and difficulty accessing services differed among NFCSP clients who reported limited long-term benefits from use of NFCSP services. The following null hypothesis was tested –

> $HB1_0$: There's no variation among client characteristics for reporting limited long-term benefit from use of NFCSP services

The new dichotomous measure capturing "limited long-term benefit" was recoded into a secondary outcome variable of interest (1=limited long-term benefit) to facilitate logistic regression. First, a series of simple logistic regressions were conducted to estimate the individual odds ratios for examining each client characteristics' influence on reporting limited long-term benefits (Table 3.9). Multiple logistic regression was conducted to assess if each of these characteristics changed within a full model, when controlling for other co-variates. Multiple logistic regression was also used to explore changes in a reduced model that included only the co-variates that were statistically associated with limited long-term benefit ($p<.20$). A likelihood ratio test (LRT) was conducted to determine if any differences existed between the full and reduced models concerning goodness-of-fit, specifically whether constraining the number of variables included in the full model to the reduced model makes a difference in the interpretation and significance of results. Results from the LRT found no difference between the full and reduced models ($p=.37$). An F-adjusted Hosmer-Lemeshow test (Archer and Lemeshow, 2006) also found that the full model suggested no evidence of lack of fit ($p=.45$) between observed and expected models.

**Figure 3.1. Organizing Framework for Caregiver Interventions**

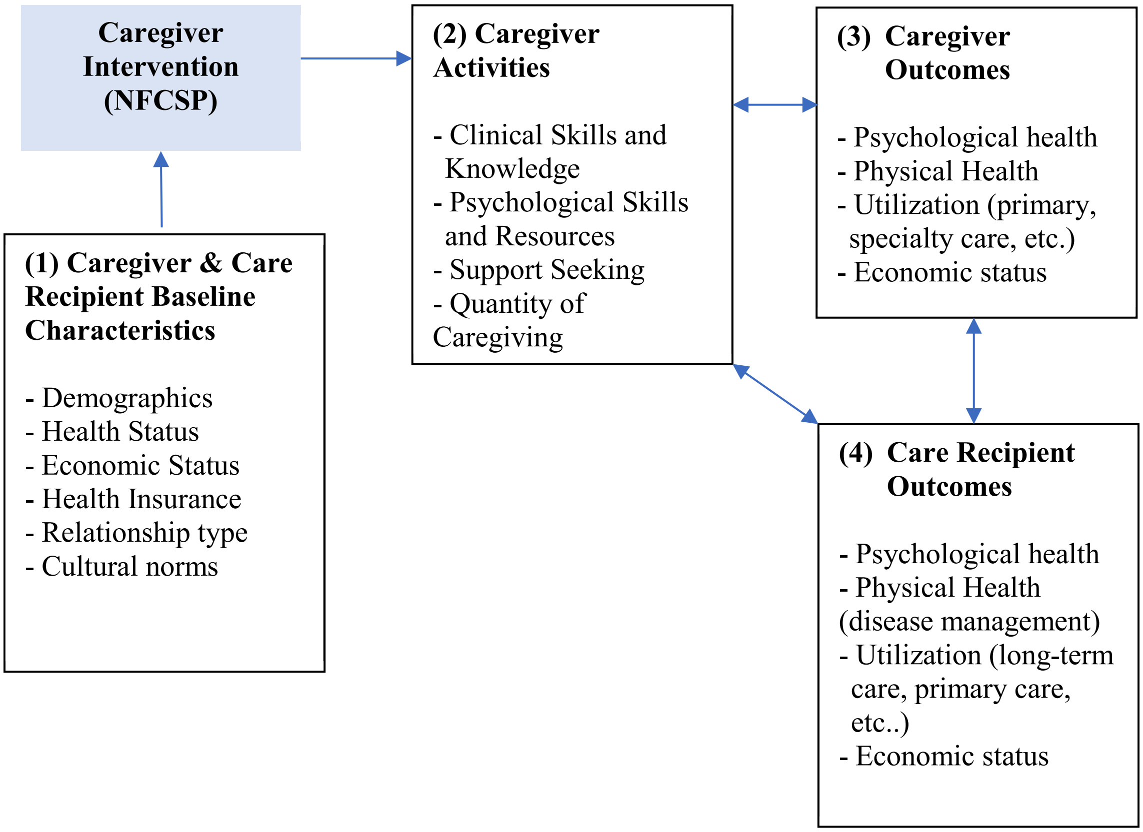


**Table 3.1. Summary descriptions of NFCSP client's characteristics, caregiving circumstances and utilization of the program services**

| NFCSP Client Characteristics | % Responses (n=1,651) | Item Non-Response (%) |
|---|---|---|
| **Demographic Characteristics** | | |
| **Caregiver Age** | | |
| 18-59 years | 25.38 | .24 |
| 60-74 years | 48.52* | |
| 75 years and older | 25.86 | |
| **Caregiver Gender** | | |
| Male | 27.74 | 1.82 |
| Female | 70.44* | |
| **Caregiver Race/Ethnicity** | | |
| White or Caucasian | 78.07* | 2.30 |
| Black or African American | 15.93 | 2.30 |
| Hispanic, non-White | 7.51 | 1.57 |
| Other | 3.39 | 2.48 |
| **Marital Status** | | |
| Married | 71.84* | 1.39 |
| Separated/Not-Married | 26.77 | |
| **Caregiver Highest Education** | | |
| High School or Less | 32.10 | .67 |
| Some college/Voc/Tech | 39.07* | |
| Bachelor's Degree | 13.08 | |
| Some post-grad/Advance degree | 15.08 | |
| **Home location** | | |
| Urban | 41.49* | 1.21 |
| Suburban | 24.47 | |
| Rural | 33.83 | |
| **Annual Income** | | |
| $0- $25,000 | 15.38 | 23.08 |
| $25,001 - $50,000 | 32.16 | |
| Above $50,000 | 29.38 | |
| **Employment Status** | | |
| Working Full Time | 16.41 | .42 |

| | | |
|---|---|---|
| Working Part Time | 9.99 | |
| Retired | 55.54* | |
| Not working | 17.63 | |
| **Relationship with care recipient** | | |
| Husband | 18.29 | 0 |
| Wife | 26.53 | |
| Son | 9.39 | |
| Son-in-law | .41 | |
| Daughter | 34.46 | |
| Daughter-in-law | 1.88 | |
| Other | 9.02 | |
| **Caregiver's Health Characteristics** | | |
| **Overall Health** | | |
| Excellent-Very Good | 32.95 | .3 |
| Good | 35.19* | |
| Fair-Poor | 31.56 | |
| **Has current disability or physical condition** | 41.85 | .48 |
| **Caregiving's impact on caregiver's health** | | |
| Created or worsened physical conditions/disabilities | 53.98* | 3.47 |
| **Level of strain associated with caregiving** | | |
| No/little amount of strain | 35.37* | 1.33 |
| Moderate amount of strain | 29.68 | |
| A lot/very high amount of strain | 33.62 | |
| **Level of stress associated with caregiving** | | |
| No/little amount of stress | 26.77 | .67 |
| Moderate amount of stress | 27.80 | |
| A lot/very high amount of stress | 44.76* | |
| **Level of financial hardship associated with caregiving** | | |
| No/little amount of financial hardship | 45.67 | 1.39 |
| Moderate amount of financial hardship | 23.44 | |
| A lot/very high amount of financial hardship | 29.50 | |
| **Care recipient Demographic and Health Characteristics** | | |

| | | |
|---|---|---|
| **Care recipient's age** | | |
| 60-74 years | 23.74 | .91 |
| 75-84 years | 34.77 | |
| 85 years and older | 40.58* | |
| **Care recipient's gender** | | |
| Male | 27.74 | 1.82 |
| Female | 70.44* | |
| **Care recipient's social benefits** | | |
| Foods stamps | 10.90 | .18 |
| Medicaid | 20.29 | 1.64 |
| Housing assistance | 11.21 | .36 |
| **Care recipient's overall health** | | |
| Excellent-Very Good | 10.30 | .79 |
| Good | 25.14 | |
| Fair-Poor | 63.74* | |
| **Diagnosed with Alzheimer's/Dementia** | 59.60* | .85 |
| **ADL Limitations** | | |
| 3+ ADL limitations | 67.29 | 2.85 |
| **Caregiver's Duties and Responsibilities** | | |
| **Caregiving responsibilities** | | |
| Help with dressing, eating, bathing or getting to the bathroom | 76.38* | .18 |
| Help with medical needs | 87.40* | .06 |
| Help with financial matters | 89.46* | .12 |
| Help with preparing meals, doing laundry or cleaning house | 92.37* | 0 |
| Help with going to doctor's appointments or shopping | 94.85* | .12 |
| Help with arranging care or services provided by others | 90.31* | .67 |
| **Number of hours of help the caregiver provide per day** | | |
| 10 hours or less | 36.64 | 4.97 |
| More than 10 hours | 58.39* | |
| **Length of years providing care** | | |

| | | |
|---|---|---|
| Less than 2 years | 14.05 | .24 |
| 2 to 5 years | 38.22 | |
| More than 5 years | 47.47* | |
| | | |
| **Distance from care recipient** | | |
| In the same house | 76.44* | .24 |
| Less than 20 minutes away | 17.26 | |
| More than 20 minutes away | 6.05 | |
| | | |
| **Number of people in which the caregiver is caring for in addition to the care recipient** | | |
| 0 | 77.71* | .06 |
| 1 or more | 22.23 | |
| | | |
| **Length of time the care recipient can be left home alone** | | |
| Can be left alone over a day | 7.09 | .3 |
| Can be left alone but checked | 10.96 | |
| Needs someone at least part of the day | 22.11 | |
| Needs someone all/nearly all the time | 59.54* | |
| **Utilization of the NFCSP services and supports** | | |
| **Assistance/Information to connect to available services** | 68.02* | 1.94 |
| | | |
| **Respite care** | **59.36*** | .42 |
| In-home respite | 87.04* | 0 |
| Adult day care | 19.49 | .10 |
| | | |
| **Training, education and counseling** | **33.25** | .73 |
| Education or Training | 46.63 | .36 |
| Counseling | 41.17 | .55 |
| Support Groups | 55.19 | .18 |
| | | |
| **Supplemental services** | | |
| Home modifications | 14.72 | .61 |
| Nutritional supplements | 13.39 | .55 |
| Walkers/canes/crutches | 21.20 | 1.51 |
| Emergency response system | 17.14 | 1.33 |
| Specialized medical equipment | 17.75 | .67 |
| Money or stipend | 16.78 | .73 |

|  |  |  |
|---|---|---|
| **Where caregivers heard about NFCSP services** |  |  |
| Family | 12.96 | 4.18 |
| Friends | 16.29 |  |
| Physician | 16.41* |  |
| Community organization | 7.93 |  |
| Media | 6.72 |  |
| Social/Case worker | 9.33 |  |
| Hospital | 8.30 |  |
| State Office on Aging | 12.36 |  |
| Other | 5.51 |  |
| **Perceived impact of NFCSP services and supports** |  |  |
| **Most useful NFCSP service and supports** |  |  |
| Respite care | 49.35* | 2.52 |
| Assistance/Information to connect to available services | 16.91 |  |
| Training, education and counseling | 10.89 |  |
| Supplemental and other services | 20.33 |  |
| **Information was helpful** | 76.49* | 2.58 |
| **As result of the services that were received -** |  |  |
| More time for personal activities | 65.17* | 1.39 |
| Feel less stress | 74.68* | 1.64 |
| Easier to care for recipient | 83.65* | 2.00 |
| Understand how to get needed services | 75.11* | 2.24 |
| Know more about care recipient's condition/illness | 61.72* | .91 |
| Care recipient benefits from services | 93.40* | 1.15 |
| Provide care longer | 75.47* | 5.39 |
| Enable care recipient to remain in the home | 58.09* | 4.54* |
| Help with caregiving-related difficulties | 71.62* | 2.26 |
| **Difficulty getting services** | 31.56 | 4.66 |
| **Overall NFCSP rating** |  |  |
| Excellent to Good | 92.85* | .85 |
| Fair to Poor | 6.30 |  |

Source: 2016 National Survey of Older Americans Act Clients – Caregiver Modules; Unweighted

*Indicates the survey response where non-responses were recoded

**Table 3.2. Summary descriptions of 2008 NFCSP client's characteristics, caregiving circumstances and utilization of the program services**

| NFCSP Client Characteristics | % Responses (n=1,623) | Item Non-Response (%) |
|---|---|---|
| **Demographic Characteristics** | | |
| **Caregiver Age** | | |
| 18-59 years | 34.07 | .49 |
| 60-74 years | 39.99* | |
| 75 years and older | 25.45 | |
| **Caregiver Gender** | | |
| Male | 26.86 | .37 |
| Female | 72.77* | |
| **Caregiver Race/Ethnicity** | | |
| White or Caucasian | 81.76* | .80 |
| Black or African American | 13.99 | .80 |
| Hispanic, non-White | 3.82 | .37 |
| Other | 3.08 | 1.23 |
| **Marital Status** | | |
| Married | 72.52 | .37 |
| Separated/Not-Married | 27.11 | |
| **Caregiver Highest Education** | | |
| High School or Less | 44.80 | .62 |
| Some college/Vocational/Technical | 33.52 | |
| Bachelor's Degree | 10.10 | |
| Some post-grad/Advance degree | 10.97 | |
| **Home location** | | |
| Urban | 39.80 | .92 |
| Suburban | 21.81 | |
| Rural | 37.46 | |
| **Employment Status** | | |
| Working Full Time | 18.73 | .37 |
| Working Part Time | 10.41 | |
| Retired | 50.77* | |
| Not working | 19.72 | |
| **Relationship with care recipient** | | |

| | | |
|---|---|---|
| Husband | 17.07 | 0 |
| Wife | 25.69 | |
| Son | 8.69 | |
| Son-in-law | .10 | |
| Daughter | 36.72* | |
| Daughter-in-law | 2.59 | |
| Other | 9.06 | |
| **Caregiver's Health Characteristics and Caregiving-related Burdens** | | |
| **Overall Health** | | |
| Excellent-Very Good | 33.09 | .43 |
| Good | 34.38* | |
| Fair-Poor | 32.10 | |
| **Has current disability or physical condition** | 40.67 | .74 |
| Caregiving has created or worsened physical conditions/disabilities | 53.03* | 2.42 |
| **Amount of strain associated with caregiving** | | |
| No/little amount of strain | 36.48* | 1.05 |
| Moderate amount of strain | 29.64 | |
| A lot/very high amount of strain | 32.84 | |
| **Amount of stress associated with caregiving** | | |
| No/little amount of stress | 27.91 | 1.36 |
| Moderate amount of stress | 27.72 | |
| A lot/very high amount of stress | 42.95* | |
| **Amount of financial hardship associated with caregiving** | | |
| No/little amount of financial hardship | 45.78* | 2.28 |
| Moderate amount of financial hardship | 24.46 | |
| A lot/very high amount of financial hardship | 27.48 | |
| **Diagnosed with Alzheimer's/Dementia** | 51.94* | .62 |
| **Utilization of NFCSP Services and Supports** | | |
| **Assistance/Information to connect to available services** | 74.00* | 1.85 |

|  |  |  |
|---|---|---|
| **Respite care** | 57.42 | .37 |
| In-home respite | 85.62* | 0 |
| Adult day care | 16.95 | .11 |
| **Training, education and counseling** | 30.56 | .37 |
| **Supplemental services** |  |  |
| Home modifications | 15.65 | .86 |
| Nutritional supplements | 11.89 | .86 |
| Walkers/canes/crutches | 27.54 | 2.09 |
| Emergency response system | 20.33 | 1.17 |
| Specialized medical equipment | 21.50 | .86 |
| Money or stipend | 18.55 | 1.91 |

Source: 2008 National Survey of Older Americans Act Clients – Caregiver Modules; Unweighted

*Indicates the survey response where non-responses were recoded

**Table 3.3. Variables summarized and/or analyzed in Chapters 4 and 5**

| | Chapter 4 | | Chapter 5 | |
|---|---|---|---|---|
| Caregiver (CG) and Care Recipient (CR) Characteristics | Summary of 2016 NSOAAP-CM Responses, stratified by CR Dementia Diagnosis | Comparing 2008 and 2016 NS0AAP-CM | Proximal outcome: Difficulty accessing services | Distal outcome: Limited or no long-term benefits |
| CG Age | X | | X | X |
| CG Gender | X | | X | X |
| CG Race and Ethnicity | X | | X | X |
| CG Marital Status | X | | X | X |
| CG Highest Education | X | | X | X |
| CG Home Location | X | | X | X |
| CG Relationship with care recipient | X | | X | X |
| CR Age | X | | X | X |
| CR Gender | X | | X | X |
| CR Social Benefits | X | | X | X |
| CR Overall Health | X | | X | X |
| CR Dementia/ Alzheimer Diagnosis | X | X | X | X |
| CG Responsibilities | X | | X | X |
| CG Number of hours of help provided per day | X | | X | X |
| CG Number of years providing care | X | | X | X |
| CG Distance from CR | X | | X | X |
| Length of time CR can be left can be left home alone | X | | X | X |
| Number of people CG provides care | X | | X | X |
| CG Overall Health | X | | X | X |
| CG Has current disability or physical condition | X | | X | X |
| CG Amount of physical strain associated with caregiving | X | X | X | X |
| CG Amount of emotional stress associated caregiving | X | X | X | X |

| | | | | |
|---|---|---|---|---|
| CG Amount of financial hardship associated with caregiving | X | X | X | X |
| Use of individual NFCSP Services and Supports | X | X | X | X |
| Where CG heard about NFCSP | X | | | |
| Overall NFCSP Rating | X | | | |
| Most useful NFCSP service | X | | | |
| Perceived Benefits after using NFCSP: | X | | | |
| - More time for personal activities | X | | | Summary Measure/Main Outcome – 'Limited long-term benefit from program use' |
| - Feel less stress | X | | | |
| - Easier to care for CR | X | | | |
| - Help deal with caregiving-related difficulties | | | | |
| - CR benefits from NFCSP services | X | | | |
| - Understand how to get services | X | | | |
| - Information was helpful | X | | | |
| - Difficulty accessing services | X | | Main Outcome | X |
| - Know more about the CR's condition or illness | X | | | |
| - Provide care longer | X | | | |
| - CR remains in the same residence | X | | | |

**Table 3.4. NFCSP client characteristics stratified by income categories and non-responses**

| Caregiver Demographic Characteristics | NFSCP Client Annual Income | | | |
|---|---|---|---|---|
| | $0-$20,000 | $20,001-$50,000 | $50,000+ | Non-responses |
| **Caregiver Age** | | | | |
| 18-59 years | 29.53 | 18.83 | 30.72 | 24.93 |
| 60-74 years | 44.09 | 48.59 | 52.37 | 46.46 |
| 75 years and older | 25.59 | 32.58 | 16.70 | 28.86 |
| **Caregiver Gender** | | | | |
| Male | 30.71 | 34.09 | 25.77 | 19.42 |
| Female | 68.50 | 64.60 | 72.37 | 77.43 |
| **Caregiver Race** | | | | |
| White or Caucasian | 70.47 | 80.98 | 85.57 | 69.55 |
| Black or African American | 23.23 | 14.69 | 11.55 | 18.37 |
| Hispanic, non-White | 13.39 | 6.59 | 4.95 | 8.14 |
| **Marital Status** | | | | |
| Married | 53.15 | 70.24 | 83.30 | 71.92 |
| Separated/Not-Married | 46.85 | 29.38 | 16.49 | 22.83 |
| **Caregiver Highest Education** | | | | |
| High School or Less | 57.09 | 34.65 | 13.61 | 35.35 |
| Some college/Voc/Tech | 33.07 | 44.26 | 38.97 | 35.96 |
| Bachelor's Degree | 6.30 | 12.24 | 19.38 | 10.76 |
| Some post-grad/Advance degree | 3.54 | 8.47 | 28.04 | 15.49 |
| **Home location** | | | | |
| Urban | 50.39 | 41.81 | 36.70 | 41.21 |
| Suburban | 14.96 | 24.48 | 32.37 | 20.73 |
| Rural | 33.86 | 33.33 | 30.31 | 34.65 |
| **Employment Status** | | | | |
| Working Full Time | 6.69 | 9.60 | 29.07 | 16.27 |
| Working Part Time | 8.66 | 11.11 | 10.72 | 8.40 |
| Retired | 48.43 | 61.58 | 50.93 | 57.74 |
| Not working | 36.22 | 17.51 | 9.28 | 16.01 |
| **Relationship with care recipient** | | | | |
| Husband | 22.44 | 23.73 | 13.40 | 14.17 |
| Wife | 20.47 | 31.64 | 22.68 | 28.35 |
| Son | 9.06 | 9.79 | 10.10 | 8.14 |
| Son-in-law | .39 | .19 | .82 | .26 |

|  |  |  |  |  |
|---|---|---|---|---|
| Daughter | 35.83 | 26.74 | 40.21 | 37.01 |
| Daughter-in-law | .79 | 1.51 | 3.09 | 1.57 |
| Other | 11.02 | 6.40 | 9.96 | 10.50 |

Source: 2016 National Survey of Older Americans Act Clients – Caregiver Modules; Unweighted

**Table 3.5. Assessing the influence of the ability of the NFCSP clients to access services without difficulty with other immediate and long-term program outcomes**

| Immediate and Long-term Program Outcomes | Primary Outcome – NFCSP client reports difficulty accessing services<br>Bivariate Model Unadjusted OR (95% CI) |
|---|---|
| **After using NFCSP services,** | |
| Clients have more time for personal activities | .42 (.27-.63)*** |
| Helped clients deal with caregiving-related difficulties | .42 (.32-.55)*** |
| Clients feel less stress | .54 (.36-.83)** |
| Easier for clients to care for care recipient | .45 (.24-.86)* |
| Care recipients have benefitted from services | .85 (.54-1.32) |
| Information was helpful to clients in connecting you to available services and resources | .43 (.25-.73)** |
| Clients understanding of how to get services you need | .25 (.17-.39)*** |
| Clients know more about care recipient condition/ illness | .68 (.50-.94)* |
| Services and supports enable care recipient to continue to remain in the same residence | .94 (.68-1.32) |
| Clients can provide care longer | .44 (.30-.64)*** |

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 3.6. Regression analysis of potential associations between NFCSP clients and care recipient characteristics and difficulty accessing services (a portion of this table appears as Chapter 5, Table 3)**

| | **Proximal Outcome: NFCSP clients report difficulty accessing services and supports** | | |
|---|---|---|---|
| **Caregiver and Care Recipient Characteristics** | **Bivariate Model Unadjusted Odds Ratio (OR) (95% CI)** | **Full Model Adjusted Odds Ratio (aOR) (95% CI)[1]** | **Reduced Model Adjusted Odds Ratio (aOR) (95% CI)[1]** |
| **Caregiver Characteristics** | | | |
| Age - 65 years and older | 0.59 (0.38-0.91)* | 0.53 (0.33-0.85)** | 0.49 (0.33-0.76)** |
| Gender – Male | 0.72 (0.48-1.08) | 0.93 (0.58-1.47) | 0.89 (0.57-1.36) |
| Race/Ethnicity – White (vs. non-White) | 0.47 (0.30-0.74)** | 0.50 (0.30-.85)** | 0.51 (0.32-.86)* |
| Married (vs. not-married) | 0.70 (0.51-.97)* | 0.89 (0.60-1.35) | 0.85 (0.61-1.18) |
| Some college/vocational training (vs. HS or less) | 1.39 (0.99-2.97) | 1.48 (0.86-2.55) | 1.45 (0.89-2.36) |
| Bachelor's degree and more (vs. HS or less) | 1.24 (0.83-1.83) | 1.25 (0.86-1.31) | 1.21 (0.69-2.15) |
| Home Location – Urban (vs. Suburban) | 0.99 (0.66-1.48) | 0.99 (0.61-1.63) | |
| Home Location – Rural (vs. Suburban) | 0.88 (0.65-1.20) | 1.13 (0.70-1.82) | |
| Retired (vs. non-retired) | 0.68 (0.44-1.04) | 0.91 (0.59-1.40) | .94 (0.60-1.49) |
| Relationship with CR – Spouse (vs. Other) | 0.91 (0.45-1.87) | 0.77 (0.39-1.49) | |
| Relationship with CR – Child (vs. Other) | 1.13 (0.68-1.86) | 0.95 (0.52-1.73) | |
| **Caregiver Health Characteristics and Caregiving-related Burden** | | | |
| Overall Health - Fair-Poor | 1.58 (0.99-2.52) | 0.82 (0.46-1.48) | 0.83 (0.49-1.43) |
| Current disability or physical limitation | 1.82 (1.43-2.32)*** | 1.61 (1.07-2.43)* | 1.57 (1.07-2.31) |
| Very high amounts of physical strain | 3.18 (2.29-4.40)*** | 2.10 (1.47-3.00)*** | 2.09 (1.47-2.98)*** |
| Very high amounts of emotional stress | 2.07 (1.44-2.97)*** | 1.48 (1.02-2.14)* | 1.45 (1.06-1.98)* |
| Very high amounts of financial hardship | 3.57 (2.62-5.64)*** | 2.21 (1.31-3.75)** | 2.19 (1.29-3.70)** |

| | | | |
|---|---|---|---|
| Provides more than 10 hours of care per day | 1.64 (1.21-2.21)** | 1.34 (0.90-1.98) | 1.29 (0.88-1.91) |
| Provided more than 5 years | 1.13 (0.80-1.61) | 1.07 (0.69-1.66) | |
| Needs someone at home nearly all/all of the time | 1.84 (1.39-2.45)*** | 1.14 (0.82-1.59) | 1.10 (0.80-1.52) |
| **Care Recipient Characteristics** | | | |
| Age - 85 years and older | 0.87 (0.62-1.23) | 0.92 (0.59-1.43) | |
| Food Stamps | 1.04 (.59-1.85) | 1.15 (.60-2.22) | |
| Housing Assistance | .73 (0.27-1.99) | 0.59 (0.21-1.65) | |
| Medicaid | 0.83 (0.52-1.32) | 0.72 (0.40-1.29) | |
| Overall Health - Fair-Poor | 1.72 (1.24-2.38)** | 1.30 (0.92-1.84) | 1.33 (0.94-1.89) |
| Diagnosed with dementia | 0.98 (0.62-1.55) | 0.80 (0.44-1.45) | |
| 3+ ADL Limitations | 1.88 (1.39-2.52)*** | 1.21 (0.87-1.67) | 1.19 (0.88-1.62) |
| **Utilization of NFCSP Services and Supports** | | | |
| Assistance/Information to connect clients to available services | 0.52 (0.34-0.79)** | 0.54 (0.34-0.86)** | .55 (.34-0.88)* |
| Respite care | 1.13 (0.87-1.48) | 1.00 (0.77-1.31) | |
| Education/Training/Counseling | 0.68 (0.50-93)* | 0.84 (0.57-1.24) | 0.79 (0.59-1.08) |
| Supplemental Service - Home modifications | 1.44 (0.83-2.47) | 1.34 (0.74-2.43) | 1.40 (.79-2.46) |
| Supplemental Service - Nutritional supplements | 1.04 (0.63-1.72) | 1.00 (0.60-1.67) | |
| Supplemental Service - Walkers/canes/crutches | 0.73 (0.45-1.17) | 0.73 (0.46-1.14) | 0.74 (0.46-1.21) |
| Supplemental Service - Emergency response system | 0.74 (0.52-1.06) | 0.99 (0.64-1.53) | 0.93 (0.59-1.44) |
| Supplemental Service - Specialized medical equipment | 1.36 (0.77-2.40) | 1.25 (0.66-2.39) | |
| Supplemental Service - Money or stipend | 0.74 (0.46-1.20) | 0.74 (0.41-1.33) | 0.74 (0.42-1.32) |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

[1] Adjusted for all co-variates included in the unadjusted results.

[2] Adjusted selected characteristics based on unadjusted results (p<.20): CG age, race/ethnicity-White, marital status, education, retirement status, overall health, current disability, high levels of strain, stress and financial hardship, hours of care per day, CR can be left home alone and utilization, CR's overall health, CR's ADL limitations, and utilization of info/access to services, education/training/counselling, home modifications, walkers/canes/crutches, emergency response systems, specialized medical equipment and money or stipend.

**Table 3.7. Principal Component Analysis Results – Selected Components and related Eigenvalues – Chapter 5**

| Component | Eigenevalue | Difference | Proportion | Cumulative |
|---|---|---|---|---|
| Component 1 | 2.89 | 1.80 | .28 | .28 |
| Component 2 | 1.08 | .05 | .11 | .39 |
| Component 3 | 1.04 | .08 | .10 | .50 |

Data Source: 2016 responses to National Survey of Older Americans Act Participants; unweighted

**Table 3.8. Alignment of NFCSP client-reported benefits from NFCSP services across three factors – Percentage of 'Yes' responses and alignment by factor loadings; Reporting of summary scores (a portion of this table appears as Chapter 5, Table 1)**

| **Item Description –** | **Component 1 limited benefit to NFCSP client or care recipient** | **Component 2 Limited facilitation of information and access to services** | **Component 3 Limited ability to maintain current care arrangement** |
|---|---|---|---|
| As a result of using the NFCSP... | Percentage 'Yes' Responses (Factor loadings) | | |
| Client has more time for personal activities | 61.5% (0.36) | | |
| Helped the client deal with caregiving-related difficulties | 71.6% (0.23) | | |
| Client feels less stress | 74.5% (0.50) | | |
| Easier for client to care for care recipient | 83.6% (0.50) | | |
| Care recipient has benefitted from services | 94.2% (0.45) | | |
| Information was helpful in connecting client to available services and resources | | 78.2% (0.63) | |
| Client understanding of how to get services you need | | 75.3% (0.56) | |
| Client knows more about care recipient condition/ illness | | 63.3% (0.44) | |
| Care recipient can continue to remain in the same residence | | | 36.1% (0.36) |
| Client can provide care for a longer time | | | 78.1% (0.83) |
| **Summary Measure – Total 'Yes' Scores** | | | |
| 0 – Reports benefit on 0 items | 1.9% | 10.7% | 18.0% |
| 1 – Reports benefit on 1 item | 6.0% | 21.9% | 49.9% |
| 2 – Reports benefit on 2 items | 7.9% | 33.3% | 32.1% |
| 3 – Reports benefit on 3 items | 16.1% | 34.1% | - |
| 4 – Reports benefit on 4 items | 27.6% | - | - |
| 5 – Reports benefit on 5 items | 40.5% | - | |
| **Kuder-Richardson 20** | .66 | .39 | .30 |

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 3.9. Regression analysis assessing potential association between NFCSP client and care recipient characteristics and perceived no/limited long-term program benefits (a portion of this table appears as Chapter 5, Table 4)**

| | **Distal Outcome:<br>NFCSP clients' perception of limited or no long-term program benefit for themselves or care recipient** | | |
|---|---|---|---|
| **Caregiver and Care Recipient Characteristics** | **Bivariate Model Unadjusted Odds Ratio (OR) (95% CI)** | **Full Model Adjusted Odds Ratio (aOR) (95% CI)[1]** | **Reduced Model Adjusted Odds Ratio (aOR) (95% CI)[1]** |
| **Caregiver Characteristics** | | | |
| Age - 65 years and older | 0.70 (0.44-1.14) | 0.58 (0.29-1.17) | 0.69 (0.47-1.05) |
| Gender – Male | 1.12 (0.59-2.11) | 1.16 (0.59-2.27) | |
| Race/Ethnicity – White (vs. non-White) | 0.67 (0.40-1.11) | 0.65 (0.34-1.28) | 0.71 (0.42-1.21) |
| Married (vs. not-married) | 0.85 (0.57-1.27) | 1.00 (0.54-1.84) | |
| Some college/vocational training (vs. HS or less) | 1.31 (0.77-2.26) | 1.21 (0.70-2.10) | |
| Bachelor's degree and more (vs. HS or less) | 0.98 (.61-1.60) | 0.94 (0.50-1.75) | |
| Home Location – Urban (vs. Suburban) | 0.96 (.65-1.42) | 0.90 (0.56-1.44) | |
| Home Location – Rural (vs. Suburban) | 1.20 (.84-1.71) | 1.26 (0.77-2.05) | |
| Retired (vs. non-retired) | .98 (.58-1.66) | 1.67 (0.84-3.31) | |
| Relationship with CR – Spouse (vs. Other) | 0.80 (.33-1.94) | 0.95 (0.42-2.15) | |
| Relationship with CR – Child (vs. Other) | 0.86 (.86-1.99) | 1.11 (0.45-2.72) | |
| **Caregiver Health Characteristics and Caregiving-related Burden** | | | |
| Overall Health - Fair-Poor | 1.37 (.97-1.93) | 1.18 (0.69-2.01) | |
| Current disability or physical condition | 0.99 (.64-1.52) | 0.66 (0.42-1.05) | |
| Very high amounts of physical strain | 2.03 (1.23-3.35)** | 1.90 (1.00-3.63)* | 1.62 (0.88-2.97) |
| Very high amounts of emotional stress | 1.45 (1.13-1.87)** | 1.49 (0.95-2.35) | 1.45 (0.91-2.32) |
| Very high amounts of financial hardship | 1.64 (1.14-2.35)** | 1.14 (0.62-2.10) | 1.01 (0.59-1.72) |
| Provides more than 10 hours of care per day | 1.41 (0.98-2.04) | 1.46 (0.90-2.37) | 1.41 (0.94-2.10) |
| Provided care for more than 5 years | 0.87 (0.47-1.63) | 0.93 (0.50-1.74) | |
| Needs someone at home nearly all/all of the time | 1.02 (.67-1.56) | 0.72 (0.41-1.26) | |

| | | | |
|---|---|---|---|
| **Care Recipient Characteristics** | | | |
| Age - 85 years and older | 0.85 (.54-1.33) | 0.77 (0.49-1.21) | |
| Food Stamps | 0.98 (.45-2.11) | 1.25 (0.50-3.12) | |
| Housing Assistance | 0.79 (.18-3.47) | 0.80 (0.16-3.94) | |
| Medicaid | 0.90 (.54-1.51) | 0.91 (0.43-1.93) | |
| Overall Health - Fair-Poor | 1.21 (.75-1.94) | 0.95 (0.57-1.57) | |
| Diagnosed with dementia | 1.21 (.80-1.81) | 1.63 (1.01-2.61)* | |
| 3+ ADL Limitations | 0.90 (.58-1.39) | 0.81 (0.47-1.40) | |
| **Utilization of NFCSP Services and Supports** | | | |
| Assistance/Information to connect clients with available services | 0.59 (.34-1.05) | 0.61 (0.38-0.99)* | 0.64 (.40-1.03) |
| Respite care | 0.37 (.24-.57)*** | 0.23 (0.14-0.39)*** | 0.25 (0.15-0.41)*** |
| Education/Training/Counseling | 0.45 (.27-.75)** | 0.31 (0.18-0.55)*** | 0.36 (0.20-.66)** |
| Supplemental Service - Home modifications | 0.63 (.39-1.03) | 0.50 (0.26-0.96)* | 0.47 (0.24-.89)* |
| Supplemental Service - Nutritional supplements | 0.86 (.39-1.87) | 0.81 (0.34-1.91) | |
| Supplemental Service - Walkers/canes/crutches | 0.56 (.27-1.14) | 0.62 (0.25-1.49) | 0.58 (0.24-1.40) |
| Supplemental Service - Emergency response system | 0.61 (.40-.94)* | 0.73 (0.40-1.35) | 0.68 (0.36-1.29) |
| Supplemental Service - Specialized medical equipment | 0.95 (.57-1.58) | 0.81 (0.43-1.52) | |
| Supplemental Service - Money or stipend | 0.81 (.48-1.37) | 0.84 (0.49-1.46) | |
| Difficulty accessing services and supports | 2.20 (1.30-3.71)** | 1.67 (1.00-2.13)* | 1.53 (0.89-2.62) |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

[1] Adjusted for all co-variates included in the unadjusted results.

[2] Adjusted selected characteristics based on unadjusted results (p<.20): CG age, race/ethnicity-White, high levels of strain, stress and financial hardship, hours of care per day, and utilization of assist/info to connect to services, respite care, education/training/counselling, home modifications, walkers/canes/crutches, emergency response systems, and money or stipend.

# CHAPTER 4: NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM: EXAMINING PROGRAM CLIENTS AND COMPARING CHARACTERISTICS AND USE OF SERVICES BETWEEN DEMENTIA AND NON-DEMENTIA CAREGIVERS

**Key Words:** Family caregiving; support services; federal policies

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## ABSTRACT

The National Family Caregiver Support Program (NFCSP) is the largest and only federal program that is specifically devoted to serving family caregivers of older adults as the defined beneficiary. Little is known about characteristics of recent NFCSP clients, or how program utilization may have changed over time, especially among dementia caregivers. This study draws from the 2008 and 2016 National Surveys of Older Americans Act Participants – Caregiver Modules to fill these information gaps. Overall, we find that NFCSP clients are predominantly white (78.6%), married (75.4%), female (74.1%) and care for an older adult with dementia (61.8%). Dementia clients who use NFCSP have higher amounts of responsibilities, physical strain and emotional stress, as well as more likely to receive information/assistance to connect clients with available services ($X^2$=6.6, p<.05), respite ($X^2$=21.4, p<.01) and training, education or counseling ($X^2$=79.4, p<.01). Between 2008 and 2016, NFCSP clients' use training, education and counseling significantly declined ($X^2$=199.4, p<.05) including among dementia caregivers. Overall, the NFCSP program is perceived positively by clients. Data from this study confirms the program's efforts to prioritize dementia caregivers who report higher amounts of strain and stress but were found to receive more core intense services.

## Introduction

The National Family Caregiver Support Program (NFCSP) is the first and only widely available federal program that is devoted to providing direct support to family caregivers as the primary client or consumer (NFCSP website). Enacted by Congress in 2000 as part of the Older Americans Act (H.R. 782, Sec. 316. 106th Cong. (2000)), the NFCSP provides funding and flexibility to states and local communities to offer a comprehensive range of services. In 2015, the NFSCP served over 750,000 clients, providing millions of contacts to family caregivers with outreach, information and assistance in identifying local support services. Counselling, education and training was provided to more than 116,000 caregivers to help them better cope with stresses of caregiving. And, an estimated 6.3 million hours of respite care and temporary relief was provided to over 67,000 family caregivers across all 50 states and territories within an annual appropriation of about $150 million (ACL, 2018; NFSCP Website; AGID Database). NFCSP services are intended to alleviate the physical, psychological and mental stressors that are often associated with caregiving to enable families to provide care longer and avoid or delay the placement of care recipients in costlier institutional care settings (NFCSP website; Foster and Kleinman, 2011). However, very little is known about recent NFCSP clients' demographic and health characteristics, their caregiving experiences, what services they receive, or perceptions of NFCSP benefits overall or for high-risk subgroups.

### *Dementia caregivers*

In a 2006 amendment to the Older Americans Act (H.R 6197. Sec. 321. 109th Cong. (2006)), Congress prioritized increasing support for family members providing care for persons with dementia as well as support for caregivers with the greatest social and economic needs. Previous studies have established the greater duration and intensity of care-related tasks that dementia caregivers perform (Ory et al., 1999; Chiao et al., 2015; Kasper, et al., 2015) which places them at increased risk for mental, physical and financial hardship due to caregiving (Ory et al., 1999). Findings are mixed as to whether dementia caregivers are more likely to seek support services to alleviate care-related stressors (Ory et al., 1999; Phillipson et al, 2014), although respite care, support groups and multicomponent interventions when accessed can improve caregiver-related stress (Gitlin et al., 2003; Spiker et al., 2008; Chien et al, 2011; Lykens et al., 2014; Jenson et al, 2015; Vandepitte et al., 2016). Gaining a better understanding of how NFCSP clients' characteristics, experiences, service utilization and program perceptions varies by their care recipient's dementia status is therefore of both programmatic and policy interest.

### *Previous NFCSP Studies*

Limited research and analyses of the NFCSP have been undertaken to date. Early studies described states' initial efforts and related challenges in implementing or expanding caregiver services using NFCSP funding (Feinberg, Newman & Van Steenberg, C., 2002; Feinberg & Newman, 2004; Whittier, Scharlach, & Dal Sando, T., 2005 and Feinberg & Newman, 2006). Subsequent studies examined early evidence of the program's utilization and effectiveness but such analyses have been limited to a small geographical area (Chen, Hendrick & Young, 2009; Chen, 2014). Although the program annually surveys a sample of family caregivers directly as part of a larger national assessment of Older American Act (OAA) program clientele, only one ACL-commissioned research brief (Foster and Kleinman, 2011) and one peer-reviewed article (Herrera et al., 2013) have drawn on these surveys to describe the demographic characteristics of NFCSP clients and their utilization of program supports and services using program data. Both analyses relied on data that are now more than 8 years old and neither examined differences by dementia status.

### *Study Purpose and Implications*

This study draws upon the most recently conducted national survey to describe and comparatively examine NFCSP clients' characteristics, caregiving experiences and utilization of NFCSP services by the dementia status of the persons they assist. We additionally examined whether and how the 2006 congressional mandate along with a stagnant budget may have affected NFCSP by comparing service use by dementia status at two points in time that approximate the inception of programmatic changes, between 2008 and 2016. Results from this study are particularly timely for several reasons. First, providing information about the types of family caregivers served by the NFCSP, their level of care-related stresses, burdens and responsibilities, the type of services provided and perceived benefits from the program is important in establishing that the program is reaching the at-risk populations it is intended to serve. Summarizing the perspectives of NFCSP clients will complement a recent analysis conducted by ACL and AoA to assess the perspectives of program administrators at the state and local level (Lewin, 2016).

Second, understanding differences in NFCSP clients who assist older adults with and without dementia is of great relevance to the National Alzheimer's Program Act (NAPA) in its effort to build upon and leverage federal efforts to change the trajectory of dementia care. Third, the NFCSP has experienced budget stagnation and even decreases (from \$153 million in 2008 to \$150 million in 2016) due to overall reductions in federal funding (ACL, 2011; ACL, 2018). Therefore, understanding any temporal changes among NFCSP client attributes and experiences can infer composition and availability of services, as well as whether service delivery has differentially affected clients by dementia status.

## Methods

### *Data Collection*

AoA assesses NFCSP client experiences annually through the National Surveys of Older Americans Act Participants (NSOAAP) – Caregiver Modules (NSOAAP-CM), a telephone-based survey (via contractor) that is conducted as part of a broader outreach to their clients who receive services through their OAA programs and assess program performance (AoA, 2008; AoA, 2016). Family caregivers who have received services through the NFCSP during the prior year were asked questions concerning their demographic background, the type of care they provide provided, caregiving related burdens, impact of caregiving on employment, health of caregiver, health and physical functioning of care recipient, and service information and perceptions about the impact of the program on both themselves and their care recipients.

This study relied on two waves of the NSOAAP-CM that were administered using comparable design and survey measures, therefore affording the ability to make comparisons between the 2008 and 2016 cohorts. We examined the 2008 NSOAAP-CM as it was the first year in which client data was assessed subsequent to the 2006 amendment to the Older Americans Act.

The sample selection for the NSOAAP-CM survey involved a two-stage sampling process (AoA, 2008; AoA, 2016). The first stage included a stratified sample of 300+ Areas Agencies on Aging (AAAs) (allowing for a 20% non-response rate) within a sampling frame of 600+ agencies based on AAA agency size and number of people served. The AAAs included in the sample were selected independently within five budget-size strata. The AAA and clients were then proportionally allocated by size within each stratum.

The largest AAAs (based on budget) were selected with certainty and the remaining AAAs were randomly selected within each of the remaining strata (AoA, 2008; AoA, 2016). The four regional Census Regions (Northeast, Midwest, South and West) were used as stratification variables in the selection process. Along with AAA size, the number of agencies in each Census Region was selected roughly in proportion to the overall AAA budget within the Region. Client samples were drawn randomly within each sampled AAA (AoA, 2008; AoA, 2016). The total number of clients who received each service within an AAA was obtained by contacting either the sampled agencies or State Units on Aging. Clients were then randomly selected by AAA using a software application.

For 2008 cohort, a post-stratification adjustment was made for specific caregiver services (AoA, 2008). Caregiver clients were categorized into three groups according to which service were received – respite care, counseling and supplemental services. Post-stratified weights were created for each of the three subgroups of clients who received respite, counseling and supplemental services, respectively.

### *Study Population*

While predominantly known for providing direct support for family caregivers of older adults (60 years and older), the NFCSP also provides support for a very small number of older adults, such as grandparents, who may care for young children (up to 18 years) and parents caring for adults with disabilities (18-59 years). As the focus of this study is on family caregivers caring for older adults, parents and grandparents were excluded. Approximately 1,709 total NFCPS clients were interviewed in the 2016 national survey and 1,651 included in the final sample to be used to describe the current demographic, health, caregiving and service utilization characteristics of program users. For the 2008 survey, 1,629 caregivers were interviewed total with 1,623 included in the final sample for the purposes of this study.

### *Measures*

We examined NFCSP clients' demographic and health characteristics, caregiving circumstances, utilization of services and perceived program benefits. Clients' demographic characteristics included age, gender, race, marital status, education level, geographic location, and employment status. Family caregivers' relationship to the care recipient were categorized as 'Daughter', 'Wife', 'Husband', 'Son' and 'Other'.

We examined a variety of measures related to NFCSP client's situation and circumstances. First, we assessed care recipient age, gender and types of financial assistance received such as food stamps, Medicaid, and housing assistance. Health-related measures included care recipient's overall health status and whether the care recipient had received a diagnosis of Alzheimer's disease or dementia.

Caregiving circumstances refers to caregiver role and responsibilities. We examined NCFSP clients' reports of providing assistance with a range of tasks including: 'helping with dressing, eating and getting to the bathroom', 'help with medical needs', 'health with financial matters', 'help with preparing meals, doing laundry or cleaning house,' 'help with going to doctor's appointments or shopping', and 'help with arranging care or services provided by others.' Caregivers were asked the number of hours of help that they provide per day ('0-10 hours', '11-23 hours', and '24 hours') as well as how long they had been providing care for their family member ('less than 2 years', '2 to 5 years', and 'more than 5 years'). Additional measures relating to caregiving circumstances included travel time distance between caregiver and care recipient place of residence, ability of the care recipient to be home alone, and number of additional persons involved in providing help.

Measures of family caregivers' health and related stressors included self-rated health and presence of a current disability or physical condition. Those who reported having a health problem, physical condition or disability, were additionally asked whether their caregiving circumstance contributed to the current disability or physical condition. Physical strain, emotional stress and financial hardship that clients attribute to their caregiving circumstances were measured using a dichotomous measure ('No/little amount of ____' to 'Very high amount of ____').

We examined NFCSP clients' reported use of each of the program's core services and supports -- respite care, assistance and information, training/education/counseling, and supplemental services (home modifications, nutritional supplements, walkers/canes/crutches, specialized medical equipment, and money or stipend. For those who used respite care, NFCSP clients were asked whether their services were received in-home and/or in adult day care. NFCSP clients were also asked where they heard about the program. NFCSP client perceptions of the program included their overall rating of program, the service or support clients perceived most useful, and specific benefits and consequences due to receipt of program supports and services.

### *Data Analysis*

Descriptive and summary statistics were used to examine demographic and health characteristics of NFCSP clients and care recipients, the type and length of the care provided by NFCSP clients, utilization of NFCSP supports and services and perceptions of the benefits derived from the program's use. These analyses were stratified by dementia status of care recipients to assess the magnitude and statistical significance of group differences. Chi-square tests were used to compare group differences between non-dementia and dementia caregivers.  We additionally sought to assess similarities and differences in NFCSP clients and service use between 2008 and 2016. by dementia status. The samples from 2008 along with the 2016 were combined with observations from both the 2008 and 2016 OAA-CM survey waves weighted using replicate weights that were included in the survey. All analyses were conducted using STATA version 12, incorporating the SVY command to account for the complex survey sample design.

## Results

### *NFCSP Client Demographic Characteristics*

Table 4.1 presents the demographic characteristics of NFCSP clients. Although 61.8% of NFCSP clients cared for someone diagnosed with dementia or Alzheimer's Disease, very few differences by dementia status were observed among the majority of demographic characteristics. NFCSP clients were found to be more often female (74.1%), White (78.6%), married (75.4%), and retired (53.9%). Daughters and daughters-in-laws represented the single largest group of clients (37.8%). Most NFCSP clients had educational attainment beyond high school (70.8%). NFCSP clients primarily reside in urban (43.7%) or suburban (28.3%) areas; less than 1/3 lived in rural regions (28.0%).

### *Caregiving Circumstances*

NFCSP clients' caregiving circumstances are shown in Table 4.2. More than half of care recipients were female (73.6%) and reported to be in fair or poor health (62.2%). About 1 in 5 care recipients were enrolled in Medicaid (19.7%) and fewer received food stamps (10.2%) or housing assistance (3.7%). Non-dementia caregivers were more likely than dementia caregivers to report assisting an older adult who received who received the three types of social benefits.

NFCSP clients perform an extensive number of caregiving-related tasks (Table 4.2), including helping with doctor's appointments and shopping (94.5%), preparing meals and household chores (92.4%), arranging care and services (89.7%), financial matters (89.7%), helping with medical needs (85.8%), and dressing, eating, bathing, and getting to the bathroom (74.9%). Dementia caregivers were generally more likely than non-dementia caregivers to perform each of these tasks as well as report providing 24 hours of care per day on average (32.1% versus 21.5%). The majority of NFCSP clients reported providing care for 2 or more years (83.0%), living with the care recipient (76.0%) and helping just one care recipient (75.0%). Dementia caregivers were more likely than non-dementia to report that the care recipient requires someone else in the home all or nearly all of the time (70.2% versus 41.3%).

Most NFCSP clients described their overall health as either excellent or very good (36.1%) or good (35.0%), with more than 1 in 4 (28.9%) rating their health as fair or poor (Table 4.2). Approximately 41.7% of NFCSP clients reported a disability or physical condition and among these NFCSP clients. For these disabled NFCSP clients, over half reported that performing their caregiving duties created, worsened, or further impaired their physical condition, especially among dementia caregivers (63.4% versus 49.7%). While NFCSP clients attribute considerable levels of at least moderate stress and strain to caregiving, dementia caregivers were especially more likely to report higher amounts of physical strain (36.4% versus 30.1%) and emotional stress associated with providing care (54.3% versus 32.9%) compared with non-dementia caregivers. Overall, about one-third of NFCSP clients (31.6%) reported financial hardship regardless of dementia status.

### *Utilization of NFCSP Services*

More than half of NFCSP clients received assistance or information to connect them to available support services (69.3%) or respite care (52.5%), while fewer received training, education or counseling (36.0%; Table 4.3). A greater proportion of dementia caregivers were found to be more likely to receive assistance or information (71.6% versus 65.6%), respite care (57.0% versus 45.3%) and training, education or counseling services (44.7% versus 23.0%) compared with non-dementia caregivers. For respite care, dementia caregivers were more likely to receive specifically adult day care services (27.4% versus 4.3%) while non-dementia caregivers, were more likely to receive respite care services in the home (92.3% versus 84.3%). Overall, supplemental services were less widely used, but most often involved access to walkers/canes/crutches (21.6%), specialized medical equipment (16.9%), emergency response system (16.5%), and money or stipend (14.1%). Non-dementia caregivers were more likely than dementia caregivers to receive home modifications (18.4% versus 12.7%) and specialized medical equipment (20.4% versus 14.1%). NFCSP clients reported hearing about the program through varied sources, including friends (17.5%), physicians (16.8), and the state office on aging (15.6%).

### *Perceptions of the NFCSP Services and Supports*

NFCSP clients favorably described services and supports offered through the program: most (93.4%) rated the program either 'Excellent' or 'Good'. Respite care (45.2%) was reported to be the most useful service among the program's features, especially among dementia caregivers (48.1% versus 39.5%; Table 4.4). NFCSP clients' use of NFCSP's services and supports benefitted care recipients (94.2%), found it easier to care for the care recipient (83.6%), had a clearer understanding of how to get needed services (75.3%), and felt less stress (74.5%). Some perceptions of the program varied by care recipients' dementia status. Dementia caregivers were more likely to report that the program enabled them to learn or know more about the care recipient's condition or illness compared with non-dementia caregivers (67.6% versus 56.3%) and perceived the program as more helpful in dealing with caregiving-related difficulties (75.0% versus 65.9%). However, a higher proportion of non-dementia caregivers reported finding it easier to care for the care recipient (87.2% versus 81.4%) and benefitting the care recipients (96.3% versus 92.9%) after utilizing the program.

### *Comparing 2008 and 2016 NFCSP Clients*

A similar proportion of NFCSP clients reported caring for a person diagnosed with dementia in 2008 and 2016 (Table 4.5). Amounts of physical strain, emotional stress and financial hardship were similar at both time periods, as were NFCSP clients' use of respite care and most supplemental services. A statistically significant reduction was found in the proportion of NFCSP clients who received training, education and counseling between 2008 and 2016, from 62.0% to 36.4%. This same reduction was also mirrored among significant shifts in the utilization of these services among dementia caregivers (see Supplemental Table).

## Discussion

Given the breadth, importance, and endurance of the NFCSP, remarkably little attention has been directed toward assessing the NFCSP's clients, their caregiving circumstances and responsibilities, utilization of services and how the program may be meeting their needs and their ability to provide care longer.  This study helps to fill this evidence gap by contributing comprehensive information about NFCSP clients and examining differences by dementia status. We find that NFCSP clients are primarily white women caring for an older adult with dementia. Dementia caregivers who use the program provide care of greater intensity and report much higher amounts of caregiving-related physical stress and emotional strain compared to non-dementia NFCSP clients. Potentially as a result, dementia caregivers are also more likely to receive extensive support through assistance or information connecting them available services, respite care and training, education and counseling. Although the NFCSP clients generally perceived the program positively, the number of NFCSP clients served and use of key services – most notably, training, education, and counseling, declined significantly between 2008 and 2016, a period which saw the program's budget remain relatively flat.

### *Characteristics of NFCSP Clients*

Typical NFCSP clients are overwhelmingly White, female, married, retired, and daughters with most having at least some college experience and a third with a college degree. These demographic characteristics broadly match most recent national profiles of caregivers providing care for older adults (Moon & Dilworth-Anderson, 2014; Wolff et al., 2017). While the NFCSP does not limit access to services and supports based on income, the 2006 Amendment to the Older Americans Act emphasized increased outreach and enrollment to those with the greatest societal and economic needs. We found low representation of NFCSP clients who assisted older adults enrolled in Medicaid, food stamps, or housing assistance. Findings from this study are consistent with prior evidence indicating that NFCSP clients are generally well educated even among minority caregivers (Herrera et al, 2014). Socioeconomic status rather than race or ethnicity may influence uptake of caregiver support, with less educated and lower income caregivers facing perceived and real barriers to service use within their communities or the ability to access information about available support (Ho et al 2000). Half of states have prioritized efforts to increase the awareness and utilization of NFCSP services among low income family caregivers (Lewin, 2016) in light of concerns that perceptions of costs or an inability to traverse the program's bureaucracy could present considerable barriers in utilization (Winslow, 2003). Findings from this study support the importance and potential need to amplify further outreach efforts.

A key difference between NFCSP clients and caregivers in other national surveys is the representation of dementia caregivers. Over half of NFCSP clients care for someone with dementia, while only a quarter of family caregivers represented in recent national survey include dementia caregivers (Moon &Dilworth-Anderson, 2014; Wolff, et al., 2017). As a result, recent national surveys also include less representation of caregivers reporting substantial emotional, physical and financial difficulty compared with NFCSP clients (Wolff, J. et al., 2017). However, further analysis of national surveys comparing the caregiving-related burden among dementia and non-dementia caregivers found differences in emotional health, similar to findings in this study.

### *Utilization of NFCSP Services*

Recent national surveys have noted the low percentage of caregivers who seek support services (Wolff et al., 2016; Ruffin et al., 2017; Wolff et al., 2017). Multiple studies note key differences between dementia and non-dementia caregivers in the use of services which is also confirmed in this study. The key focus of the NFCSP is to provide information and directly assist caregivers with services and supports based on their and their care recipient particular needs. Among these services, respite care was received by about half of all NFCSP clients and was most widely reported to be the most useful service or support received, notably among dementia caregivers. The importance of respite is notable as half of NFCSP clients report providing care more than 10 hours a day and more than one-quarter report providing care around the clock in addition to experiencing high levels of physical strain and emotional stress. While widely available, some states and local AAAs cap the number of respite care hours, which may lead to lengthy wait lists (up to 6 months) for both in-home and adult day care services (Lewin Group, 2016), and therefore deter service use.

Like respite care, most states offer some form of training, education and/or counseling through the NFCSP (Lewin Group, 2016), although less than half of all NFCSP clients utilized such services based on the 2016 survey. Analysis of NFCSP client data revealed that the majority of users of training, education and counseling were dementia caregivers. Despite being more likely to receive training, education, or counseling, less than half of the dementia caregivers used this more intensive form of support which can provide an opportunity to meet other caregivers, learn more about dementia and develop coping strategies to address and cope with increasing frequencies of care recipients' memory and behavioral problems (Robinson, Buckwalter & Reed, 2005; Dal Santo et al, 2007; Scharlach et al, 2008; Beeber, Thorpe & Clipp, E., 2008; NFCSP website). Although not causal, the program's ability to provide opportunities to learn more about the recipient's condition and help clients cope with the difficulties associated with caregiving were more often reported by dementia NFCSP clients.

Although the NFCSP offers a diverse selection of supplemental services, only half of states offer a complete range of these services (Lewin Group, 2016). Notably, only a quarter of the states provide cash grants to family caregivers through NFCSP (Lewin Group, 2016). For the more than half of NFCSP clients who report experiencing at least some financial hardship associated with caregiving only one in ten NFCSP clients reported receiving cash or a stipend through the program. The lack of universal cash grants represents a potential important service gap.

### *Potential Implications from Decrease and Stagnation of NFCSP Budget*

The NFCSP budget remained relatively stagnant between 2008 and 2016 ($153 million to $150 million) (ACL, 2011; ACL, 2018) while also facing additional requirements to provide more evidenced-based programs for caregivers and care recipients (H.R 6197. Sec. 305(3)(D). 109th Cong. (2006)). A potential consequence might be the decrease in the number of family caregivers served by the NFCSP and the ability to provide services at the same level of intensity. For example, the number of NFCSP clients who received education, training and counseling declined by more than 20% since 2008, translating into more than 20,000 fewer clients per year receiving such services based on the latest program data (AGID Database), despite the program serving a comparable percentage of dementia caregivers during this time period. For dementia caregivers alone, education and training programs aimed at increasing caregiver knowledge and mastery has been shown to improve competence, management of the situation, help manage expectations, improve reactions to disruptive behaviors and reduce caregiver depression (Gitlin et al., 2003; Spijker, et al., 2008; Chien et al, 2011; Samia, Hepburn & Nichols, 2012; Brodaty & Arasaratnam, 2012; Lykens, K et al., 2014; Jenson et al., 2015; Vandepitte  et al., 2016). Reduced availability of such services may hinder program effectiveness and undermine the ability of the program to respond to Congressional mandates that seek to prioritize this critical group of family caregivers.

### *Study Limitations*

This study is subject to a number of data constraints. As a cross-sectional study, we are unable to assess the effects of NFCSP services over a long period of time, and any implied causality must be viewed with caution. Second, study participants were comprised NFCSP clients and we were therefore unable to comparatively examine results relative to those who did not seek services.  Our measure of dementia derived from caregiver reports and may not account care recipients who may be under-diagnosed. Finally, we are not able to assess the level of variability of offerings and availability services and supports for NFCSP clients across the AAAs.

## Conclusion

For more than 15 years, the NFCSP has served an important role in supporting millions of family caregivers of older adults. This study leverages recent program data to contribute new knowledge regarding characteristics of NFCSP clients, their caregiving circumstances, the services and supports they use and whether they benefit from the services and supports they receive, especially among dementia caregivers.

NFCSP clients, however, are representative of a small number of family members compared to an estimated 18-40 million family caregivers providing uncompensated care for an aging parent, spouse, relative or friend (Chari et al, 2014; Spillman et al, 2014;

Reinhard et al, 2015; BLS, 2015). Although many family caregivers cope well or derive significant benefit from their helping role (Roth et al, 2015), others may experience caregiving-related physical, psychological and mental stressors that can be alleviated through programs such as the NFCSP. NFCSP administrators report increasing demand within the constraints of limited or decreasing funding (Lewin, 2016). Stagnant funding has and will limit the program's ability to enable states and communities to increase their capacity to serve more family caregivers over time. This is currently evident in the program's decrease and delay in the availability of services such as respite care and training/education/support groups (Lewin, 2016).

Overall, NFCSP clients rate the program highly and perceived benefits align well with program goals of alleviating stress, facilitating access to services and resources, and enabling their ability to provide care for a longer duration. However, it is not clear if all clients benefit equally from the program. Further research is needed to identify the characteristics of NFCSP clients who experience difficulty accessing services and derive limited long-term benefits from the program's supports and services, informing targeted strategies for further program improvement and prioritizing of services and supports amid continuing budget constraints.

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**Table 4.1. NFCSP client demographic and health characteristics by Alzheimer's disease (AD)/ dementia status of care recipients**

| Caregiver Demographic Characteristics | Total Sample n = 1,651 | % AD/ Dementia 'Yes' | % AD/ Dementia 'No' | Comparison |
|---|---|---|---|---|
| **Care recipient has AD/Dementia** | | **61.8**% | **38.2**% | |
| **Caregiver Age** | | | | |
| 18-59 years | 26.2% | 23.9% | 29.9% | $X^2$=9.3 |
| 60-74 years | 49.3% | 49.7% | 48.5% | |
| 75 years and older | 24.5% | 26.4% | 21.5% | |
| **Caregiver Gender** | | | | |
| Male | 25.9% | 25.1% | 27.4% | $X^2$=1.1 |
| Female | 74.1% | 74.9% | 72.6% | |
| **Caregiver Race and Ethnicity** | | | | |
| White or Caucasian | 78.6% | 79.6% | 77.2% | $X^2$=1.3 |
| Black or African American | 16.4% | 14.2% | 20.0% | $X^2$=9.5* |
| Hispanic | 9.9% | 10.6% | 8.7% | $X^2$=1.7 |
| **Marital Status** | | | | |
| Married | 75.4% | 75.3% | 75.7% | $X^2$=.0 |
| Non-Married | 24.6% | 24.7% | 24.3% | |
| **Caregiver Highest Education** | | | | |
| High School or Less | 29.2% | 27.6% | 31.6% | $X^2$=3.2 |
| Some college/vocational training | 40.1% | 40.7% | 39.3% | |
| Bachelor's degree | 13.2% | 13.4% | 12.8% | |
| Some post-graduate | 17.5% | 18.3% | 16.3% | |
| **Home Location** | | | | |
| Urban | 43.7% | 46.7% | 39.0% | $X^2$=9.6 |
| Suburban | 28.3% | 27.1% | 30.1% | |
| Rural | 28.0% | 26.2% | 30.9% | |
| **Employment Status** | | | | |
| Working Full Time | 17.5% | 16.8% | 18.6% | $X^2$=3.3 |
| Working Part Time | 11.6% | 11.3% | 12.0% | |
| Retired | 53.9% | 53.6% | 54.4% | |
| Not working | 17.0% | 18.3% | 15.0% | |

| | | | | |
|---|---|---|---|---|
| **Relationship with care recipient** | | | | |
| Husband | 16.7% | 16.3% | 17.5% | $X^2=.8$ |
| Wife | 26.6% | 27.0% | 25.9% | |
| Son/Son-in-law | 10.2% | 10.4% | 9.9% | |
| Daughter/Daughter-in-law | 37.8% | 37.5% | 38.3% | |
| Other | 8.6% | 8.8% | 8.4% | |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 4.2. NFCSP client caregiving circumstances and health characteristics by Alzheimer's disease (AD)/ dementia status of care recipients**

| Care Recipient Demographic and Health Characteristics | Total Sample n = 1,651 | % AD/ Dementia 'Yes' | % AD/ Dementia 'No' | Comparison |
|---|---|---|---|---|
| **Care Recipient's Age** | | | | |
| 60-74 years | 24.6% | 18.2% | 35.0% | $X^2$=59.1*** |
| 75-84 years | 34.0% | 37.3% | 28.6% | |
| 85 years and older | 41.4% | 44.5% | 36.4% | |
| **Care Recipient's Gender** | | | | |
| Male | 26.4% | 25.5% | 27.9% | $X^2$=1.1 |
| Female | 73.6% | 74.5% | 72.1% | |
| **Care Recipient's Social Benefits** | | | | |
| Foods stamps | 10.2% | 7.7% | 14.2% | $X^2$=17.6** |
| Medicaid | 19.7% | 15.4% | 26.5% | $X^2$=30.0** |
| Housing assistance | 3.7% | 2.7% | 5.3% | $X^2$=7.2* |
| **Care Recipient's Overall Health** | | | | |
| Excellent-Very Good | 11.8% | 13.8% | 8.5% | $X^2$=11.1 |
| Good | 26.0% | 26.1% | 25.9 % | |
| Fair-Poor | 62.2% | 60.1% | 65.6% | |
| **Caregiving responsibilities** | | | | |
| Help with dressing, eating, bathing or getting to the bathroom | 74.9% | 78.6% | 69.0% | $X^2$=18.9** |
| Help with medical needs | 85.8% | 90.4% | 78.3% | $X^2$=46.7** |
| Help with financial matters | 89.7% | 92.0% | 86.1% | $X^2$=14.9* |
| Help with preparing meals, doing laundry or cleaning house | 92.4% | 94.8% | 88.6% | $X^2$=21.3* |
| Help with going to doctor's appointments or shopping | 94.5% | 95.9% | 92.2% | $X^2$=10.4* |
| Help with arranging care or services provided by others | 89.7% | 91.8% | 86.5% | $X^2$=11.7* |
| **Number of hours of help the caregiver provides per day** | | | | |
| 0 - 10 hours | 44.5% | 36.7% | 57.1% | $X^2$=65.4*** |
| 11- 23 hours | 27.4% | 31.2% | 21.4% | |

|  |  |  |  |  |
|---|---|---|---|---|
| 24 hours | 28.1% | 32.1% | 21.5% |  |
| **Number of years providing care** |  |  |  |  |
| Less than 2 years | 17.0% | 18.1% | 15.3% | $X^2$=6.0 |
| 2 to 5 years | 38.1% | 39.3% | 36.1% |  |
| More than 5 years | 44.9% | 42.6% | 48.6% |  |
| **Distance from care recipient** |  |  |  |  |
| In the same house | 76.0% | 80.2% | 69.2% | $X^2$=26.1** |
| Less than 20 minutes away | 16.3% | 13.4% | 20.9% |  |
| More than 20 minutes away | 7.7% | 6.4% | 9.9% |  |
| **Length of time the care recipient can be left home alone** |  |  |  |  |
| Can be left alone over a day | 8.5% | 4.4% | 15.0% | $X^2$=174.9*** |
| Can be left alone but checked | 10.3% | 5.4% | 18.2% |  |
| Needs someone at least part of the day | 22.1% | 20.0% | 25.5% |  |
| Needs someone all/nearly all the time | 59.1% | 70.2% | 41.3% |  |
| **Number of people in which the caregiver is care for in addition to the care recipient** |  |  |  |  |
| 0 | 75.0% | 76.6% | 72.5% | $X^2$=3.5 |
| 1 or more | 25.0% | 23.4% | 27.5% |  |
| **Caregiver's Health Characteristics and Related Stressors** |  |  |  |  |
| **Overall Health** |  |  |  |  |
| Excellent-Very Good | 36.1% | 34.4% | 38.9% | $X^2$=3.5 |
| Good | 35.0% | 35.6% | 34.0% |  |
| Fair-Poor | 28.9% | 30.0% | 27.1% |  |
| **Has current disability or physical condition** | 41.7% | 41.7% | 41.5% | $X^2$=.0 |
| Impact on caregiver health – Created or worsened physical conditions/disabilities | 58.2% | 63.4% | 49.7% | $X^2$=12.5* |

| | | | | |
|---|---|---|---|---|
| **Amount of physical strain associated with caregiving** | | | | |
| No/little amount of strain | 35.6% | 32.0% | 41.5% | $X^2=15.9$* |
| Moderate amount of strain | 30.3% | 31.6% | 28.4% | |
| A lot/very high amount of strain | 34.1% | 36.4% | 30.1% | |
| **Amount of emotional stress associated with caregiving** | | | | |
| No/little amount of stress | 26.1% | 18.5% | 38.3% | $X^2=97.8$*** |
| Moderate amount of stress | 27.8% | 27.2% | 28.8% | |
| A lot/very high amount of stress | 46.1% | 54.3% | 32.9% | |
| **Amount of financial hardship associated with caregiving** | | | | |
| No/little amount of financial hardship | 45.0% | 42.5% | 49.0% | $X^2=6.7$ |
| Moderate amount of financial hardship | 23.4% | 24.4% | 21.8% | |
| A lot/very high amount of financial hardship | 31.6% | 33.1% | 29.2% | |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 4.3. NFCSP client utilization of core services by Alzheimer's disease (AD)/dementia status of care recipients**

| NFCSP services and supports | Total Sample n = 1,651 | % AD/ Dementia 'Yes' | % AD/ Dementia 'No' | Comparison |
|---|---|---|---|---|
| **Assistance/Information to connect to available services** | 69.3% | 71.6% | 65.6% | $X^2$=6.6* |
| **Respite care** | 52.5% | 57.0% | 45.3% | $X^2$=21.4** |
| In-home respite care | 86.9% | 84.3% | 92.3% | $X^2$=12.1* |
| Adult day care | 19.8% | 27.4% | 4.3% | $X^2$=72.7** |
| **Training, education and counseling** | 36.4% | 44.7% | 23.0% | $X^2$=79.4*** |
| **Supplemental services** | | | | |
| Home modifications | 14.9% | 12.7% | 18.4% | $X^2$=9.8* |
| Nutritional supplements | 12.5% | 11.7% | 13.8% | $X^2$=1.7 |
| Walkers/canes/crutches | 21.6% | 19.4% | 25.1% | $X^2$=7.6 |
| Emergency response system | 16.5% | 14.1% | 20.4% | $X^2$=11.3* |
| Specialized medical equipment | 16.9% | 16.5% | 17.4% | $X^2$=.2 |
| Money or stipend | 14.1% | 14.0% | 14.2% | $X^2$=.0 |
| **Where caregivers heard about NFCSP services** | | | | |
| Family | 12.3% | 13.3% | 10.8% | $X^2$=16.9 |
| Friends | 17.5% | 17.2% | 17.9% | |
| Physicians | 16.8% | 18.0% | 14.8% | |
| Community Organizations | 9.3% | 8.8% | 10.0% | |
| Media | 6.6% | 7.0% | 5.9% | |
| Social/case worker | 8.9% | 7.8% | 10.7% | |
| Hospital | 7.6% | 6.9% | 8.6% | |
| State Office on Aging | 15.6% | 14.6% | 17.3% | |
| Other | 5.4% | 6.3% | 3.9% | |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 4.4. NFCSP clients' perception of program benefits by Alzheimer's disease (AD)/ dementia status of care recipients**

| NFCSP clients' perceptions concerning program services and supports | Total Sample n = 1,651 | % AD/ Dementia 'Yes' | % AD/ Dementia 'No' | Comparison |
|---|---|---|---|---|
| **Overall NFCSP Rating** | | | | |
| Excellent to Good | 93.4% | 93.2% | 93.7% | $X^2$=.1 |
| Fair to Poor | 6.6% | 6.8% | 6.3% | |
| **Most useful NFCSP service or support** | | | | |
| Respite care | 45.2% | 48.1% | 39.5% | $X^2$=33.2** |
| Help/Info about available services | 22.5% | 21.3% | 24.9% | |
| Training/Education/Support Groups | 13.9% | 16.0% | 9.7% | |
| Other services and assistance | 18.5% | 14.6% | 25.9% | |
| **Perceived benefits from utilizing NFCSP supports and services** | | | | |
| Information was helpful in connecting to available services and resources | 78.2% | 77.1% | 80.2% | $X^2$=1.5 |
| More time for personal activities | 61.5% | 60.1% | 63.9% | $X^2$=2.4 |
| Feel less stress | 74.5% | 73.0% | 76.9% | $X^2$=3.2 |
| Find it easier to care for care recipient | 83.6% | 81.4% | 87.2% | $X^2$=9.5* |
| Clearer understanding of how to get services you and the care recipient need | 75.3% | 73.2% | 78.8% | $X^2$=6.7* |
| Know more about the care recipient's condition or illness | 63.3% | 67.6% | 56.3% | $X^2$=21.7** |
| Care recipient benefits from NFCSP services | 94.2% | 92.9% | 96.3% | $X^2$=8.4* |
| No difficulty accessing services | 67.5% | 67.6% | 67.2% | $X^2$=.0 |
| Helped deal with difficulties that result from caregiving | 71.6% | 75.0% | 65.9% | $X^2$=15.2** |
| Provide care for a longer time than would have been possible without services | 78.1% | 79.3% | 76.1% | $X^2$=2.3 |
| Care recipient can remain in the same residence | 63.9% | 62.6% | 66.1% | $X^2$=2.0 |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 4.5. Comparison of 2008 and 2016 NFCSP clients: Care recipient's AD/dementia status and utilization of the NFCSP services and supports**

| Client Characteristics | Total Sample 2008 n = 1,623 | Total Sample 2016 n = 1,651 | Comparison |
|---|---|---|---|
| **Diagnosis of Alzheimer's/Dementia** | 60.9% | 61.8% | $X^2$=.19 |
| **Level of physical strain associated with caregiving** | | | |
| No/little amount of strain | 37.4% | 35.6% | $X^2$=1.96 |
| Moderate amount of level of strain | 30.9% | 30.4% | |
| A lot/very high amount of strain | 31.7% | 34.0% | |
| **Level of emotional stress associated with caregiving** | | | |
| No/little amount of stress | 25.0% | 26.1% | $X^2$=.65 |
| Moderate amount of stress | 27.6% | 27.8% | |
| A lot/very high amount of stress | 47.4% | 46.1% | |
| **Level of financial hardship associated with caregiving** | | | |
| No/little amount of financial hardship | 51.1% | 45.0% | $X^2$=14.1 |
| Moderate amount of financial hardship | 22.9% | 23.4% | |
| A lot/very high amount of financial hardship | 26.0% | 31.6% | |
| **Assistance/Information to connect to available services** | 75.5% | 69.3% | $X^2$=14.6 |
| **Respite care** | 52.4% | 52.5% | $X^2$=.0 |
| In-home respite care | 85.2% | 86.9% | $X^2$=1.1 |
| Adult day care | 20.2% | 19.86% | $X^2$=.0 |
| **Training, education and counseling** | 62.0% | 36.4% | $X^2$=199.4*** |
| **Supplemental services** | | | |
| Home modifications | 12.8% | 14.9% | $X^2$=2.6 |
| Nutritional supplements | 11.5% | 12.5% | $X^2$=.7 |
| Walkers/canes/crutches | 26.8% | 21.6% | $X^2$=11.0 |
| Emergency response system | 13.2% | 16.5% | $X^2$=6.4 |

| | | | |
|---|---|---|---|
| Specialized medical equipment | 18.2% | 16.9% | $X^2=1.0$ |
| Money or stipend | 13.6% | 14.1% | $X^2=.1$ |

*p< .05; **p< .01; ***p< .001

Data Source: 2008 and 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Appendix Table 4.1. Comparison of the 2008 and 2016 NFCSP clients: Dementia caregivers' use of NFCSP services and supports**

| **Client Characteristics** | **2008**<br>**n = 853** | **2016**<br>**n = 997** | **Comparison** |
|---|---|---|---|
| **Assistance/Information to connect to available services** | 79.4% | 71.6% | $X^2$=14.5 |
| **Respite care** | 56.1% | 57.0% | $X^2$=.1 |
| In-home respite care | 84.5% | 84.3% | $X^2$=.0 |
| Adult day care | 27.1% | 27.4% | $X^2$=.0 |
| **Training, education and counseling** | 67.5% | 44.7% | $X^2$=92.8** |
| **Supplemental services** | | | |
| Home modifications | 12.1% | 12.7% | $X^2$=.1 |
| Nutritional supplements | 8.1% | 11.7% | $X^2$=6.3 |
| Walkers/canes/crutches | 25.7% | 19.4% | $X^2$=9.6 |
| Emergency response system | 12.0% | 14.1% | $X^2$=1.6 |
| Specialized medical equipment | 17.4% | 16.5% | $X^2$=.2 |
| Money or stipend | 13.4% | 14.0% | $X^2$=.1 |

*p< .05; **p< .01; ***p< .001

Data Source: 2008 and 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

# CHAPTER 5: VARIATION AMONG CLIENT CHARACTERISTICS IN DIFFICULTY ACCESSING SERVICES THROUGH THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (MANUSCRIPT #3)

**Key Words:** Family caregiving; support services; federal policies

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# ABSTRACT

**Background and Objectives:** This study identified which National Family Caregiver Support Program (NFCSP) client characteristics are associated with difficulty accessing services and perceptions of limited or no long-term program benefits.

**Research Design and Methods:** This study includes a sample of 1,651 NFCSP clients who participated in the 2016 National Surveys of Older Americans Act Participants – Caregiver Module (NSOAAP-CM). Chi-square ($X^2$) and regression analyses were used to assess which client characteristics are associated with difficulty accessing support and perceptions of limited or no long-term benefits.

**Results:** NFCSP clients who were White (aOR, .50; 95% CI .30-.85; p<.01) and older than 65 years old (aOR, .53; 95% CI .33-.85; p<.01) were less likely to report difficulty accessing services. Clients with a disability or physical condition (aOR, 1.61; 95% CI 1.07-2.43; p<.05) and high levels of physical strain (aOR, 2.10; 95% CI 1.47-3.00; p<.01), emotional stress (aOR, 1.52; 95% CI 1.04-2.24; p<.05) or financial hardship (aOR, 2.21; 95% CI 1.31-3.75; p<.01) reported difficulty accessing services. Those receiving direct assistance and information to connect clients with available services were less likely to report difficulty in accessing services (aOR, 0.54; 95% CI 0.34-0.86; p<.01). Physical strain, caring for person with dementia along with reporting difficulty accessing were also found to be significantly associated with perceptions of no or limited long-term benefits from using the program.

**Discussion and Implications:** While the program is rated highly by NFCSP clients overall, we find variability in ability of the program to provide immediate and long-term benefits among its clientele. Our study suggests greater attention towards minority clients as well as clients who report high levels of stress and strain in identifying and reducing barriers and challenges to access to available NFCSP services and supports.

## Background

The National Family Caregiver Support Program (NFCSP) was launched in 2000 as the first federal program to directly support family caregivers of older adults as the intended beneficiary of services (NFCSP website). Through the NFCSP, the Administration on Aging (AoA) provides funding for State Units on Aging (SUAs) to offer a comprehensive range of services and supports that are delivered by Area Agencies on Aging (AAAs) and local service providers (LSPs). Available services include information or assistance in gaining access to supportive services for both the client and care recipient, education/training/counseling, respite care and a variety of supplemental services to support caregivers in their care of family members and friends (NFCSP website). The NFCSP reaches more than a million family caregivers annually, with the aim of reducing caregiving-related distress and delaying or preventing the institutionalization of care recipients (NFCSP website; Foster & Kleinman, 2011). Although the program is rated highly overall by NFCSP clients (Foster & Kleinman, 2011 and Liggins et al., 2018), little is known as to whether positive program benefits are uniformly experienced by those served.

Most studies of the NFCSP have examined challenges and successes of states' initial efforts to implement the NFCSP (Feinberg, Newman, & Van Steenberg, 2002; Feinberg, Newman, 2004; Feinberg & Newman, 2006). However, fewer studies have examined the differential experiences of NFCSP clients. One study of NFCSP clients residing in Seattle found that male caregivers experienced less subjective burden, higher caregiving satisfaction and higher satisfaction after utilizing the program relative to female caregivers (Chen, 2014). Another study using program data by Herrera et al

(2014) found higher unmet needs among Hispanic clients and that Black clients reported less benefit from NFCSP services with respect to averting future institutionalization relative to White clients.

Studies of caregivers’ use of community-based long-term services and support (LTSS) more broadly (other than the NFCSP) have primarily focused on identifying the factors and characteristics that affect use of caregiver services (Ho et al., 2000, Toseland et al., 2002; Robinson, Buckwalter, & Reed, 2005; Scharlach et al., 2006; Scharlach et al., 2008). Most studies have found that lack of awareness or personal preferences contribute to low uptake of service use, notably among minority caregivers. Few studies have examined the demographic and care factors of caregivers who are aware of such programs or willing to seek assistance, but who nevertheless report barriers or difficulty in accessing supports (Potter, 2018).

Although the percentage of NFCSP clients who have reported difficulty accessing services has declined from 64% in 2003 to just over 30% in 2016 (ACL, 2018) due to innovative outreach and programming at the state and local levels, elucidating factors associated with variability in accessibility to services is nevertheless important to understanding whether the program is meeting the immediate needs of its diverse target population. As family caregiving circumstances vary substantially with respect to a range of individual and contextual factors, we sought to assess variability in clients’ ability to access needed assistance across a range of demographic characteristics, caregiving circumstances and utilization of services. We also sought to understand whether such characteristics and care circumstances were also associated with limitations in attaining longer-term program benefits. Difficulty accessing services is an important measure of whether NFCSP is meeting one its most immediate program objectives and is annually reported to Congress to support annual funding appropriations (ACL, 2018). Identifying NFCSP clients who report significant barriers in accessing services can inform stakeholders as to potential gaps in program coverage in serving its diverse clientele of family caregivers.

## Methods

### *Sample*

This study relies on the 2016 National Surveys of Older Americans Act (OAA) Participants – Caregiver Modules (NSOAAP-CM), a telephone-based survey (via contractor) that was conducted as part of an organizational effort to assess programmatic performance and outreach to clients who receive services through OAA programs (AoA, 2016). Family caregivers who have received services through the NFCSP during the prior year were asked questions concerning their demographic background, the type of care they provide provided, caregiving related burdens, impact of caregiving on employment, health of caregiver, health and physical functioning of care recipient, and service information and perceptions about the impact of the program on both themselves and their care recipients.

The sample selection for the NSOAAP-CM survey involves a two-stage sampling process (AoA, 2016). The first stage includes a stratified sample of 300+ Areas Agencies on Aging (AAAs) (allowing for a 20% non-response rate) within a sampling frame of 600+ agencies based on AAA agency size and number of people served as well as budget-size strata. The AAA and clients are then proportionally allocated by size within each stratum; the largest AAAs (based on budget) are selected with certainty and the remaining AAAs are randomly selected within each of the remaining strata (AoA, 2016) as well as by Census Region. At the second stage of sampling, clients who received specific NFCSP services (respite, counseling, and supplemental services) are selected within each of the sampled AAAs or State Units on Aging.

### *Study Population*

While predominantly known for providing direct support for family caregivers of older adults (60 years and older), the NFCSP also provides support for a smaller number of older adults, such as grandparents, who care for young children (up to 18 years) and parents caring for adults with disabilities (18-59 years). As the focus of this study is on family caregivers of older adults, NFCSP clients who self-identified as a parent or grandparent were excluded. Of 1,709 NFCPS clients who responded to the 2016 national survey, 1,651 clients met this studies' eligibility criteria and were included in this analysis.

### *Organizing Framework*

This study draws upon an organizing framework (Van Houtven, Voils & Weinberger, 2011) to assess any potential associations between NFCSP client characteristics with proximal and distal outcomes (Figure 5.1). Survey questions from the 2016 NSOAAP-CM were individually mapped onto the organizing framework's four constructs. First, client and care recipient demographic and health characteristics (Construct 1) can inform the type of caregivers who may both utilize and benefit from the program as well as the care circumstances and arrangements that may induce the use of services and supports. NFCSP program data captures the proximal or immediate impact on clients after seeking support through the program (Construct 2), including understanding how and the ability to access needed services as well as the actual utilization of services. Potential distal or longer-term benefits and outcomes NFCSP clients (Construct 3) and for care recipients (Construct 4), have implications for the program's overall goals, which include reducing caregiving-related stress and enabling care recipients to remain in their home.

## Measures

### *Outcome measures*

Difficulty Accessing NFCSP Services – The primary outcome in this study was derived from NFCSP client responses to the question 'Has it been difficult for you to get services from agencies for the care recipient?' with Yes/No responses recoded to Difficulty/No difficulty (1=Difficulty).

Limited Long-Term Benefit – In the development of the secondary outcome, we relied on 10 questions to assess whether and how the program has affected NFCSP clients and care recipients long-term. Dichotomous (yes/no) responses were used to construct a summary measure indicating whether clients derived limited long-term benefits from using NFCSP services. These 10 questions were mapped to Constructs 3 and 4 from the organizing framework including caregiving interventions' impact on the physical and psychological health of caregivers and care recipients and also, further use of health care.

Principal component analysis (PCA) was performed for the purposes of reducing the 10 questions to a manageable set of key components or constructs that were used to inform construction composite measures. PCA identified three components based on factor loadings and Eigenvalues greater than 1.0 (Kaiser's criterion), which explained 50.2% of the variance (Princeton DSS, STATA) (Table 5.1). Five questions related to NFCSP's ability to potentially improve the physical and mental health of clients and care recipients in the longer term loaded onto Component 1 (Table 5.1), which demonstrated far higher internal consistency as compared with Components 2 and 3 (KR-20 α= .66, .39 and .40 respectively). Component 1 encompassed factors central to clients' perceived long-term benefits from using NFCSP services for both themselves and their care recipient(s) (Construct 3 and 4).

A summary measure of "limited long-term benefit" was constructed by summing 'Yes' responses to the 5 items that loaded onto Component 1, resulting in an index ranging from 0 to 5, where higher values indicated greater benefit from clients' use of NFCSP services. To delineate clients who derived more or limited benefit, a cut point was made at the lowest quintile (0-2) with the higher scores representing greater benefit collapsed together (3-5). The newly created dichotomous measure was recoded (1='limited long-term benefit') to facilitate further regression analyses. Using this criterion, approximately 15.8% clients were categorized as perceiving limited long-term benefits for themselves or their care recipient from their use of NFCSP services.

### *Covariates*

We examined NFCSP client demographic and health characteristics, caregiving related stressors, caregiving circumstances, and utilization of the NFCSP supports and services. *Demographic characteristics* included NFCSP client age, gender, marital status, employment (not retired/retired), geography (rural/city/suburban), education (high school or less/some college/bachelor's degree and more), Race/ethnicity (White/Black/Hispanic), and relationship to the care recipient (spouse/child/other). Measures of *NFCSP client health status and caregiving burden* included overall health (excellent to good/fair-poor), whether NFCSP reported experiencing a physical limitation or disability and physical strain (no-moderate amount/very high amount), emotional stress (no-moderate amount/very high amount) and financial hardship (no-moderate amount/very high amount). *Caregiving circumstances* included hours of care per day (more or less than 10 hours), length of care (more or less than 5 years) and if the care recipient can be left alone. Measures of *care recipient characteristics* included care recipient age (under/older 85 years old), use of social support (Food Stamps/Energy Assistance/Medicaid), overall health – Fair-Poor, dementia status, and 3+ ADL limitations. *NFCSP Services and supports* included clients' use (Yes/No) of information/assistance in accessing services, respite care, education/training/counseling, and the following supplemental services: home modifications, nutrition services, walkers/canes, emergency response equipment, specialized medical equipment, and money or stipend.

## Statistical Approach

First, we compared differences in client characteristics by virtue of whether they did or did not report experiencing difficulty in obtaining services. Chi-square ($X^2$) was used to assess whether any such differences were statistically significant. Simple logistic regression was used to assess the strength and magnitude of associations between each co-variate and the primary outcome. We then used multivariate logistic regression to examine whether NFCSP client characteristics remained statistically significant in association with difficulty accessing services after controlling all other co-variates. Potential associations between co-variates and perceptions of limited long-term program benefit was examined using simple and a full multiple regression model. As difficulty in obtaining services represents a proximal outcome and limited program benefit represents a distal outcome, we also examined the relationship between these two measures. All responses from the 2016 NSOAAP-CM were weighted to account for the complex survey sample design using the SVY command along with the survey's replicate weighs (STATA version 12)

## Results

### *Characteristics of NFCSP Clients*

This study sample included 1,651 NFCSP clients who were mostly female (74.1%), White (78.6%), married (75.4%), 65 years or older (58.7%), retired (53.9) and children of care recipients (48.0%). Most had more than a high school education (70.9%) and resided in urban (43.7%) and suburban (28.3%) areas (Table 5.2). Most NFCSP clients reported 'Excellent to Good' (71.1%) health. However, many clients reported having a disability or physical condition (42.2%) and caregiving-related physical strain (34.0%), emotional stress (46.1%) or financial hardship (31.6%). Most clients reported providing care for less than 5 years (84.6%), more than 10 hours per day (61.0%) and caring for someone who requires help at least nearly all of the time (59.1%). The majority of NFCSP clients reported assisting someone between the ages of 60 and 84 years old

(59.9%), in ‘Fair-Poor’ health (62.2%), with a diagnosis of dementia or Alzheimer’s disease (61.8%) and with more than 3 activities of daily living (ADL) limitations (68.5%). Most clients reported receiving assistance and information to connect with available services (69.3%) and respite care (52.5%); fewer clients received education/training/counselling (36.4%) or supplemental services (14.1%-21.6%).

*Factors Associated with Proximal Outcome: NFCSP client reporting difficulty accessing services*

<u>NFCSP Client Demographic Characteristics.</u> The association between NFCSP client characteristics and likelihood of reporting difficulty accessing services and supports was examined in bivariate and multivariate regression models (Table 5.3). Clients who were 65 years and older, White, married and retired were less likely to report difficulty accessing. In a full multivariate model that controlled for all co-variates, White clients were 50% less likely to report difficulty accessing services compared with non-White clients (aOR, .50; 95% CI .30-.85; p<.01). Clients aged 65 and older were also less likely to report difficulty accessing services (aOR, 0.53; 95% CI 0.33-0.85; p<.01).

<u>NFCSP Client Health Characteristics and Caregiving-related Burden.</u> Clients reporting having a disability or physical limitation as well as high amounts of physical strain, emotional stress, and financial hardship were more likely to report difficulty accessing supportive services in unadjusted models. When controlling for other co-variates, NFCSP clients reporting a current disability or physical condition (aOR, 1.61; 95% CI 1.07-2.43; p<.05), high amounts of physical strain (aOR, 2.10; 95% CI 1.47-3.00; p<.01), emotional strain (aOR, 1.48; 95% CI 1.02-2.14; p<.05), and financial hardship (aOR, 2.21; 95% CI 1.31-3.75; p<.01) were more likely to report difficulty accessing NFCSP services.

Caregiving Circumstances. NFCSP clients providing care 10 or more hours per day and whose care recipients required someone at home with them nearly all or all of the time were more likely to report significant difficulty accessing services and supports in unadjusted models but did not remain significant when controlling for other co-variates in a full model.

Care Recipient Characteristics. While care recipients in fair to poor health and with more than 3 ADL limitations were associated with difficulty accessing services and supports in bivariate models, no care recipient characteristics were statistically significant in association with difficulty accessing services and supports in the multivariate model.

NFCSP services and supports. NFCSP clients who used assistance/information to connect them to available services and education/training/counselling were less likely to report difficulty accessing services in unadjusted models. The likelihood of reporting difficulty accessing services was more than 40% lower among NFCSP clients who received assistance/information to connect them to available services (aOR, 0.54; 95% CI 0.34-0.86; $p<.01$) in the full multivariate model.

### *Limited Long-term Benefit from NFCSP*

Finally, we examined variation among caregiver and care recipient characteristics, circumstances, and use of NFCSP program services and supports were associated with perceptions of limited long-term benefits for NFCSP clients and care recipients (Table 5.4). NFCSP clients reporting high amounts of physical strain, emotional stress and financial hardship were more likely to report perceptions of limited benefits for themselves and their care recipients in bivariate models. Only physical strain remained statistically significant in the full multivariate model when controlling for other significant co-variates (aOR, 1.90; 95% CI 1.00-3.63; p<.05). While caring for a person with dementia was not associated with perceptions of limited long-term program benefits in unadjusted models but was found to be associated with being more likely to report limited long-term benefits from program use when controlling for the other co-variates (aOR, 1.63; 95% CI 1.01-2.61; p<.05). NFCSP clients who used information or assistance to connect to support (aOR, 61; 95% CI .38-.99; p<.05), respite care (aOR, .23; 95% CI .14-.39; p<.01), training/education/counseling (aOR, .31; 95% CI .18-.55; p<.01) and home modifications (aOR, .50; 95% CI .26-.96; p<.05) were significantly less likely to report perceptions of limited long-term benefit in multivariate models. Finally, NFCSP clients who reported difficulty accessing services and supports were more likely to report perceptions of limited benefits in both bivariate and multivariate models (aOR, 1.67; 95% CI 1.00-2.13; p<.05).

## Discussion

A key objective of the NFCSP is to link family and unpaid caregivers with available assistance, but little is known about whether and which factors may affect NFCSP clients' ability to readily access services or if potential implications exist for longer-term program benefits. Using program data, we found that NFCSP clients who were White and older than 65 years were less likely to report difficulty accessing services. Having a current disability or physical limitation and reported high amounts of caregiving-related physical strain, emotional stress, and financial hardship were more likely to report difficulty accessing services. Importantly, clients who received assistance and information to connect to available services were less likely to report difficulty accessing support. This study also found that difficulty accessing supports can limit NFCSP's ability to provide long-term benefits for many clients. Use of assistance and information, respite care and education/training/counseling were all strongly associated with reduced likelihood of reporting limited long-term benefits by NFCSP clients. And for dementia caregivers, results indicated their ability access services without difficulty through NFCSP, however they may be deriving limited long-term benefits for themselves and their care recipient from use of NFCSP services and supports.

### *Demographic Characteristics*

Racial and ethnic disparities in the use of the caregiver services have been widely studied and reported (Scharlach et al., 2006; Scharlach et al., 2008; Hong, 2009; Casado et al., 2011; Herrera et al., 2014; Greenwood et al., 2015). These disparities have been attributed to reluctance to seek or use support services due to cultural-based perspectives regarding family responsibilities and preferences for reliance on kinship networks rather than formal services (Scharlach et al., 2006; Scharlach et al., 2008; Hong, 2009; Chow et al., 2010). In contrast, this study included minority caregivers who were indeed interested and sought assistance through the NFCSP. Our finding that White NFCSP clients reported less difficulty accessing NFCSP services compared with non-White clients is consistent with a recent article finding that minority caregivers represented in a national caregiving survey, were more likely to seek but not use caregiver support services, a measure that was interpreted by the author as difficulty accessing caregiver support (Potter, 2018). Additional research is necessary to determine whether observed findings are due to underuse of services that are found to reduce barriers to available services and supports, lower awareness of how to access services within the parameters of program, lack of transportation to get to needed services, service-related waiting times and costs and/or the type of services that are available are not what minority clients feel meets their or their care recipients' specific needs (Phillipson, Jones, & Magee, 2014; Lewin, 2016; Potter, 2018).

Clients older than 65 also were less likely to report difficulty accessing services through NFCSP. Being older than 65 years and possibly retired may afford flexibility in clients' schedules to be able to fully engage and follow-up with case managers or staff who can help guide clients towards needed services as well as participate in more intensive education/training/counseling options without having to balance competing responsibilities. While the NFCSP program's services are varied and comprehensive, the study results suggest that the program may be more limited in its ability to support clients who are younger who might need to balance work, children and aging parents. Currently, only about one-third of AAAs target outreach towards employed family caregivers and only around 13% include employed caregivers among mandatory training topics for staff and volunteers (Lewin, 2016). Further prioritization may be necessarily to ensure sufficient coverage of younger and working clientele.

### *Caregiving-related Stressors and Burden*

NFCSP clients experiencing higher amounts of caregiving related stressors and burden, notably emotional stress, physical strain and financial hardship, were more likely to report difficulty accessing services and supports through the NFCSP. Studies to assess the limited use of support services by highly stressed and burdened caregivers have previously cited apathy or an inability by physically and mentally overburdened caregivers to take action to improve their care situation (Robinson, Buckwalter, & Reed, 2005) or maybe even lacking the stamina and energy to research and pursue community services to help them manage their current care arrangement (Toseland et al., 2002). Unlike these earlier studies, this study includes highly stressed and strained NFCSP clients who were both willing and have sought the use of services and supports with the hopes of alleviating their care burden and meet the needs of their care recipient. With highly stressed and strained NFCSP clients reporting difficulty accessing services, our findings point to potential gaps in prioritization and service coverage that may limit the programs' ability to benefit clients and care recipients long-term, especially those reporting high levels of physical strain. Inability to alleviate such stressors and burdens can result in substandard or poor care, which if not addressed, can evolve into neglect and potential abuse of care recipients (Beach & Schulz, 2017) or an inability to provide care longer (Spillman & Long, 2009). Future studies should develop a fuller profile of NFCSP clients who experience higher amounts of emotional stress, physical strain and financial hardship in addition to higher caregiving burden to assess the services they may or may not be receiving.

### *NFCSP Service and Supports*

This is the first study to assess how use of individual NFCSP services may be associated with measures of immediate impacts such as difficulty accessing services as well as more longer-term outcomes related to perceived program benefits for clients and care recipients. Among the services and supports available through the program, only use of assistance and information to connect clients with available support was found to be significantly associated with less difficulty accessing program services and support. Use of assistance and information along with both respite care and education/training/counseling were all found to be associated with lower perceptions of limited program benefits for themselves and their care recipients by NFCSP clients. Use of these services enable specific long-term benefits for clients and care-recipients such as reducing stress, increasing knowledge to improve care for the care recipient, and alleviating caregiving-related difficulties and adds to previous research studies examining the effectiveness of these types of supports in helping to improve caregiving outcomes (Dal Santo et al., 2007; Spijker et al., 2008; Shaw et al., 2009; Lopez-Hartmann et al., 2012; Brown, Chen and Smith, 2012; Vandepitte et al 2016).

### *Dementia Caregivers*

NFCSP specifically prioritizes dementia caregivers in both outreach and allocation of services (Lewin, 2016; NFCSP website). While dementia caregivers in the NFCSP are more likely to report caregiving-related emotional stress and physical strain, they are also more likely to receive information and assistance, respite care and education/training/counseling compared with non-dementia caregivers (Liggins, 2018). As a potential result, study findings indicate that dementia caregivers are able to access program services without difficulty through NFCSP, meeting at least some of their immediate needs. However, findings also intimate that the use of such services are not beneficial to dementia caregivers and their care recipients long-term. Simple regression yielded a non-significant association between dementia status and long-term benefits.

Although, when controlling for other variables in a full model, a significant association was found prompting a need for further analyses to explore potential interference from one or more of other variables in the model.

### *Limitations*

This study is subject to a number of limitations. First, the development of the NSOAAP-CM survey questions was not constructed with the development of a summary measure in mind. As a result, the KR-20 alphas which were used to measure the internal consistency for the distal summary measure is lower than the desired threshold of .80. Second, a cross-sectional survey was used to capture feedback from NFCSP clients and represents subjective feedback from program users. This survey does not also allow for longitudinal assessments of NFCSP's impact to demonstrate underlying causal mechanisms. Third, the NSOAAP-CM survey was fielded to a subset of family caregivers who sought services through the NFCSP representing a small percentage of families. Their perceptions may not be generalizable to the larger population of family caregivers. Fourth, NFCSP clients may use multiple services and our findings related to services use therefore was not isolated from the range of supportive services used. Additionally, we examined NFCSP client data related to any service utilization. Among the individual services used, it's unknown how many times or sessions each service was utilized.

## **Conclusion**

Since its inception, the NFCSP has provided critical support for millions of family caregivers of older adults. While the program is rated highly by NFCSP clients, not all clients experience the program in the same way. This is the first study to examine NFCSP client characteristics that are associated with difficulty accessing services, a foundational aspect of the program's objectives. Furthermore, we also found that limitations in the program's ability to achieve proximal outcomes was also associated to limitation in distal outcomes as well. Findings suggest that information and assistance to connect clients with available support facilitates access to services, but that gaps may exist for non-White and younger caregivers, as well as those with significant levels of stress and strain. Our study suggests greater attention and prioritization of clients who are minority, working, and at risk due to extensive caregiving demands could enhance the program's ability to best meet the needs of its diverse clientele. And further research is needed fully elucidate the long-term implications of program use for dementia caregivers and their care recipients.

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**Figure 5.1. Organizing Framework for Study**

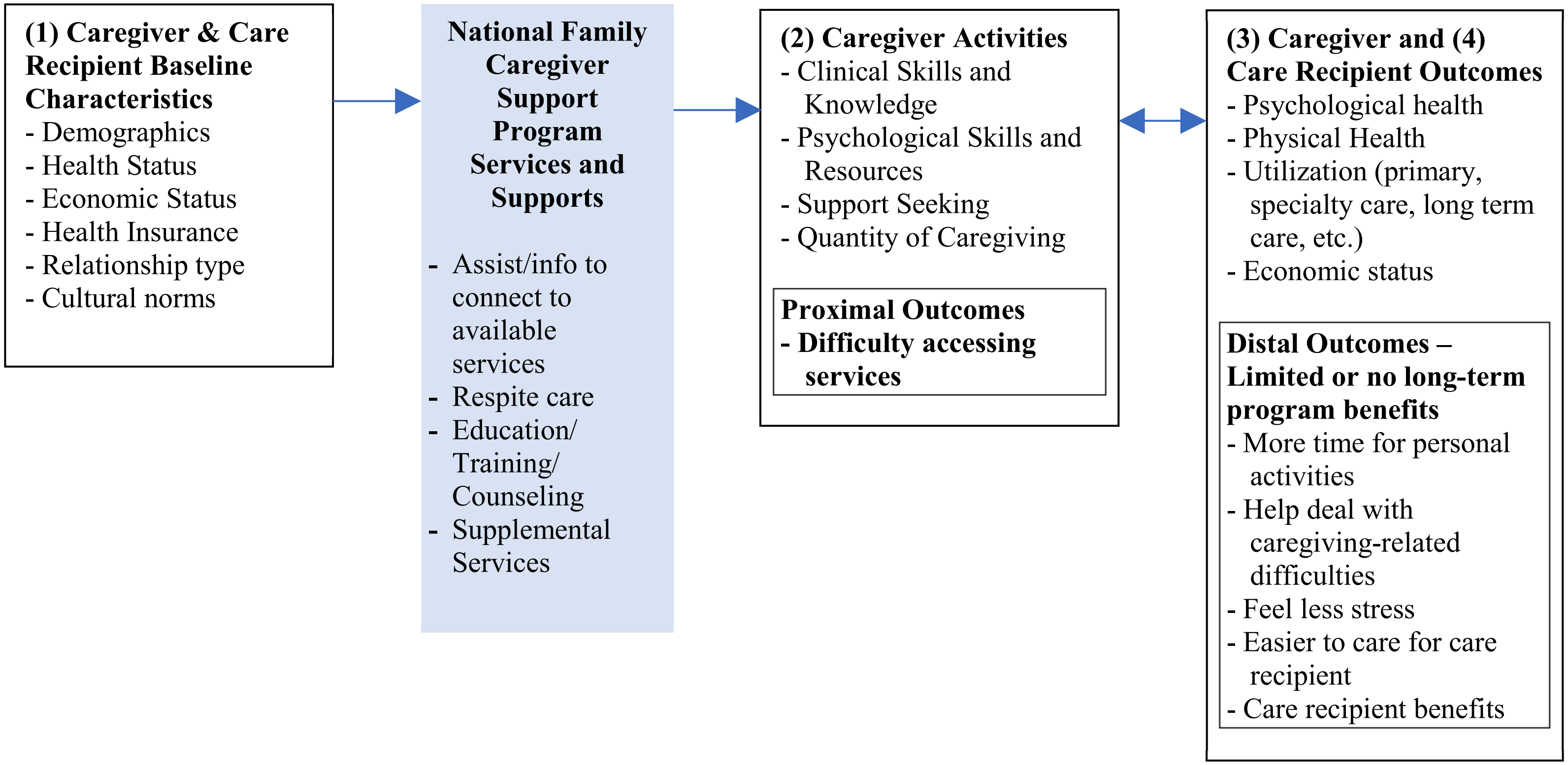

**Table 5.1. Development of Distal Outcome Measure - Contributing survey items, distribution of summary scores of no or limited benefit NFCSP and care recipients, summary measure cut point, and internal consistency measure.**

| **Item Description** – As a result of NFCSP... | **No or limited benefit of NFCSP services for client or care recipient % Yes responses (Factor Loadings)** |
|---|---|
| Client has more time for personal activities | 61.5% (0.36) |
| Helped the client deal with caregiving-related difficulties | 71.6% (0.23) |
| Client feels less stress | 74.5% (0.50) |
| Easier for client to care for care recipient | 83.6% (0.50) |
| Care recipient has benefitted from services | 94.2% (0.45) |
| **Summary Measure – Total 'Yes' Scores** | |
| 0 – Reports benefit on 0 items | 1.9% |
| 1 – Reports benefit on 1 item | 6.0% |
| 2 – Reports benefit on 2 items | 7.9% |
| 3 – Reports benefit on 3 items | 16.1% |
| 4 – Reports benefit on 4 items | 27.6% |
| 5 – Reports benefit on 5 items | 40.5% |
| **Summary measure cut point - reports benefit on 0-2 items** | **15.8%** |
| **Kuder-Richardson 20** | **.66** |

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 5.2. Client and care recipient demographic and health characteristics, caregiving circumstances and utilization of services and supports for clients who have and have not experienced difficulty accessing NFCSP services and supports**

| Caregiver Characteristics | Total Sample n = 1,651 (Unweighted) | Total = 173,064 (Weighted) | NFCSP clients who experienced difficulty in accessing services and supports | | Difference |
|---|---|---|---|---|---|
| | | | Yes (32.5%) | No (67.5%) | |
| **Caregiver Age** | | | | | |
| 18-64 years | 682 | 41.3% | 50.1% | 37.1% | $X^2$=25.1* |
| 65 years and older | 969 | 58.7% | 49.9% | 62.9% | |
| **Caregiver Gender** | | | | | |
| Female | 1,223 | 74.1% | 78.2% | 72.1% | $X^2$=7.0 |
| Male | 428 | 25.9% | 21.8% | 27.9% | |
| **Caregiver Race and Ethnicity** | | | | | |
| White | 1,298 | 78.6% | 69.6% | 83.0% | $X^2$=39.1** |
| Black | 271 | 16.4% | 24.5% | 12.5% | $X^2$=37.8*** |
| Hispanic | 163 | 9.9% | 12.7% | 8.5% | $X^2$=7.2 |
| **Marital Status** | | | | | |
| Non-Married | 406 | 24.6% | 29.1% | 22.4% | $X^2$=8.7* |
| Married | 1,245 | 75.4% | 70.9% | 77.6% | |
| **Caregiver Highest Education** | | | | | |
| High School or Less | 480 | 29.2% | 25.3% | 31.0% | $X^2$=6.7 |
| Some college/vocational training | 664 | 40.1% | 43.8% | 38.4% | |
| Bachelor's degree and more | 507 | 30.7% | 30.9% | 30.6% | |
| **Home location** | | | | | |
| Suburban | 467 | 28.3% | 29.0% | 27.9% | $X^2$=1.1 |
| Urban | 721 | 43.7% | 44.7% | 43.3% | |
| Rural | 462 | 28.0% | 26.3% | 28.8% | |
| **Employment Status** | | | | | |
| Not Retired | 761 | 46.1% | 52.5% | 43.0% | $X^2$=13.2 |

| | | | | | |
|---|---|---|---|---|---|
| Retired | 890 | 53.9% | 47.5% | 57.0% | |
| **Relationship with care recipient** | | | | | |
| Spouse | 715 | 43.3% | 40.2% | 44.9% | $X^2$=3.6 |
| Child | 792 | 48.1% | 51.3% | 46.4% | |
| Other | 144 | 8.6% | 8.5% | 8.7% | |
| **Caregiver Health Characteristics and Caregiving-related Burden** | | | | | |
| **Overall Health** | | | | | |
| Excellent-Good | 1,174 | 71.1% | 64.6% | 74.3% | $X^2$=16.5 |
| Fair-Poor | 477 | 28.9% | 35.4% | 25.7% | |
| **Has current disability or physical condition** | 697 | 41.7% | 52.1% | 37.4% | $X^2$=32.3*** |
| **Amount of physical strain associated with caregiving** | | | | | |
| No-moderate amount of physical strain | 1,090 | 66.9% | 48.1% | 74.6% | $X^2$=113.9*** |
| Very high amounts of physical strain | 561 | 34.1% | 51.9% | 25.4% | |
| **Amount of emotional stress associated with caregiving** | | | | | |
| No-moderate amount of emotional stress | 890 | 53.9% | 41.7% | 59.7% | $X^2$=47.3*** |
| Very high amounts of emotional stress | 761 | 46.1% | 58.3% | 40.3% | |
| **Amount of financial hardship associated with caregiving** | | | | | |
| No-moderate amount of financial hardship | 1,129 | 68.4% | 49.3% | 77.6% | $X^2$=134.5*** |
| Very high amounts financial hardship | 522 | 31.6% | 50.7% | 22.4% | |
| **Care Circumstances** | | | | | |
| **Number of hours of help the caregiver provides per day** | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| Less than 10 hours | 644 | 39.0% | 31.3% | 42.8% | $X^2$=20.0** |
| More than 10 hours | 1,007 | 61.0% | 68.7% | 57.2% | |
| **Length of years providing care** | | | | | |
| Less than 5 years | 1,397 | 84.6% | 83.5% | 85.2% | $X^2$=.8 |
| More than 5 years | 254 | 15.4% | 16.5% | 14.8% | |
| **Length of time the care recipient can be left home alone** | | | | | |
| Can be left alone over a day | 674 | 40.8% | 31.2% | 45.5% | $X^2$=30.8*** |
| Needs someone nearly all or all of the time | 977 | 59.2% | 68.8% | 54.5% | |
| **Care recipient characteristics** | | | | | |
| **Care recipient's age** | | | | | |
| 60-84 years | 989 | 58.6% | 62.2% | 58.8% | $X^2$=1.8 |
| 85 years and older | 662 | 41.4% | 37.8% | 41.2% | |
| **Care Recipient Gender** | | | | | |
| Female | 1,215 | 73.6% | 78.2% | 72.1% | $X^2$=7.0 |
| Male | 436 | 26.4% | 21.8% | 27.9% | |
| **Care recipient's use of social support** | | | | | |
| Housing Assistance | 61 | 3.7% | 3.0% | 4.0% | $X^2$=1.1 |
| Food Stamps | 168 | 10.2% | 10.5% | 10.1% | $X^2$=.1 |
| Medicaid | 325 | 19.7% | 17.7% | 20.6% | $X^2$=1.9 |
| **Care recipient's overall health** | | | | | |
| Excellent-Good | 624 | 37.8% | 29.5% | 41.8% | $X^2$=23.4** |
| Fair-Poor | 1,027 | 62.2% | 70.5% | 58.2% | |
| **Care recipient diagnosed with dementia** | 1,020 | 61.8% | 61.4% | 61.9% | $X^2$=.0 |
| **Care recipient has 3+ ADL limitations** | 1,131 | 68.5% | 77.2% | 64.3% | $X^2$=27.8*** |
| **Utilization of NFCSP Services and Supports** | | | | | |
| Assistance/Information to connect to available services | 1,144 | 69.3% | 59.5% | 74.0% | $X^2$=35.8** |

| | | | | | |
|---|---|---|---|---|---|
| Respite care | 867 | 52.5% | 54.6% | 51.5% | $X^2$=1.4 |
| Education/Training/Counseling | 601 | 36.4% | 30.5% | 39.2% | $X^2$=11.9* |
| Supplemental services | | | | | |
| Home modifications | 246 | 14.9% | 18.1% | 13.3% | $X^2$=6.5 |
| Nutritional supplements | 206 | 12.5% | 12.8% | 12.3% | $X^2$=.1 |
| Walkers/canes/crutches | 357 | 21.6% | 18.1% | 23.3% | $X^2$=5.8 |
| Emergency response system | 272 | 16.5% | 13.8% | 17.8% | $X^2$=4.0 |
| Specialized medical equipment | 279 | 16.9% | 19.9% | 15.4% | $X^2$=5.1 |
| Money or stipend | 233 | 14.1% | 11.8% | 15.2% | $X^2$=3.5 |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

**Table 5.3. Regression analysis of potential associations between NFCSP clients and care recipient characteristics and difficulty accessing services**

| Caregiver and Care Recipient Characteristics | Proximal Outcome: NFCSP clients report difficulty accessing services and supports | |
|---|---|---|
| | **Bivariate Model Unadjusted Odds Ratio (OR) (95% CI)** | **Full Model Adjusted Odds Ratio (aOR) (95% CI)[1]** |
| **Caregiver Characteristics** | | |
| Age - 65 years and older | 0.59 (0.38-0.91)* | 0.53 (0.33-0.85)** |
| Gender – Male | 0.72 (0.48-1.08) | 0.93 (0.58-1.47) |
| Race/Ethnicity – White (vs. non-White) | 0.47 (0.30-0.74)** | 0.50 (0.30-.85)** |
| Married (vs. not-married) | 0.70 (0.51-.97)* | 0.89 (0.60-1.35) |
| Some college/vocational training (vs. HS or less) | 1.39 (0.99-2.97) | 1.48 (0.86-2.55) |
| Bachelor's degree and more (vs. HS or less) | 1.24 (0.83-1.83) | 1.25 (0.86-1.31) |
| Home Location – Urban (vs. Suburban) | 0.99 (0.66-1.48) | 0.99 (0.61-1.63) |
| Home Location – Rural (vs. Suburban) | 0.88 (0.65-1.20) | 1.13 (0.70-1.82) |
| Retired (vs. non-retired) | 0.68 (0.44-1.04) | 0.91 (0.59-1.40) |
| Relationship with CR – Spouse (vs. Other) | 0.91 (0.45-1.87) | 0.77 (0.39-1.49) |
| Relationship with CR – Child (vs. Other) | 1.13 (0.68-1.86) | 0.95 (0.52-1.73) |
| **Caregiver Health Characteristics and Caregiving-related Burden** | | |
| Overall Health - Fair-Poor | 1.58 (0.99-2.52) | 0.82 (0.46-1.48) |
| Current disability or physical limitation | 1.82 (1.43-2.32)*** | 1.61 (1.07-2.43)* |
| Very high amounts of physical strain | 3.18 (2.29-4.40)*** | 2.10 (1.47-3.00)*** |
| Very high amounts of emotional stress | 2.07 (1.44-2.97)*** | 1.48 (1.02-2.14)* |
| Very high amounts of financial hardship | 3.57 (2.62-5.64)*** | 2.21 (1.31-3.75)** |
| Provides more than 10 hours of care per day | 1.64 (1.21-2.21)** | 1.34 (0.90-1.98) |
| Provided more than 5 years | 1.13 (0.80-1.61) | 1.07 (0.69-1.66) |
| Needs someone at home nearly all/all of the time | 1.84 (1.39-2.45)*** | 1.14 (0.82-1.59) |
| **Care Recipient Characteristics** | | |
| Age - 85 years and older | 0.87 (0.62-1.23) | 0.92 (0.59-1.43) |
| Food Stamps | 1.04 (.59-1.85) | 1.15 (.60-2.22) |
| Housing Assistance | .73 (0.27-1.99) | 0.59 (0.21-1.65) |
| Medicaid | 0.83 (0.52-1.32) | 0.72 (0.40-1.29) |
| Overall Health - Fair-Poor | 1.72 (1.24-2.38)** | 1.30 (0.92-1.84) |
| Diagnosed with dementia | 0.98 (0.62-1.55) | 0.80 (0.44-1.45) |
| 3+ ADL Limitations | 1.88 (1.39-2.52)*** | 1.21 (0.87-1.67) |

| | | |
|---|---|---|
| **Utilization of NFCSP Services and Supports** | | |
| Assistance/Information to connect clients to available services | 0.52 (0.34-0.79)** | 0.54 (0.34-0.86)** |
| Respite care | 1.13 (0.87-1.48) | 1.00 (0.77-1.31) |
| Education/Training/Counseling | 0.68 (0.50-93)* | 0.84 (0.57-1.24) |
| Supplemental Service - Home modifications | 1.44 (0.83-2.47) | 1.34 (0.74-2.43) |
| Supplemental Service - Nutritional supplements | 1.04 (0.63-1.72) | 1.00 (0.60-1.67) |
| Supplemental Service - Walkers/canes/crutches | 0.73 (0.45-1.17) | 0.73 (0.46-1.14) |
| Supplemental Service - Emergency response system | 0.74 (0.52-1.06) | 0.99 (0.64-1.53) |
| Supplemental Service - Specialized medical equipment | 1.36 (0.77-2.40) | 1.25 (0.66-2.39) |
| Supplemental Service - Money or stipend | 0.74 (0.46-1.20) | 0.74 (0.41-1.33) |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

[1] Adjusted for all co-variates included in the unadjusted results.

**Table 5.4. Regression analysis assessing potential association between NFCSP client and care recipient characteristics and perceived limited long-term program benefits**

| Caregiver and Care Recipient Characteristics | Distal Outcome: NFCSP clients' perception of limited long-term program benefit for themselves or care recipient<br>Bivariate Model Unadjusted Odds Ratio (OR) (95% CI) | Full Model Adjusted Odds Ratio (aOR) (95% CI)[1] |
|---|---|---|
| **Caregiver Characteristics** | | |
| Age - 65 years and older | 0.70 (0.44-1.14) | 0.58 (0.29-1.17) |
| Gender – Male | 1.12 (0.59-2.11) | 1.16 (0.59-2.27) |
| Race/Ethnicity – White (vs. non-White) | 0.67 (0.40-1.11) | 0.65 (0.34-1.28) |
| Married (vs. not-married) | 0.85 (0.57-1.27) | 1.00 (0.54-1.84) |
| Some college/vocational training (vs. HS or less) | 1.31 (0.77-2.26) | 1.21 (0.70-2.10) |
| Bachelor's degree and more (vs. HS or less) | 0.98 (.61-1.60) | 0.94 (0.50-1.75) |
| Home Location – Urban (vs. Suburban) | 0.96 (.65-1.42) | 0.90 (0.56-1.44) |
| Home Location – Rural (vs. Suburban) | 1.20 (.84-1.71) | 1.26 (0.77-2.05) |
| Retired (vs. non-retired) | .98 (.58-1.66) | 1.67 (0.84-3.31) |
| Relationship with CR – Spouse (vs. Other) | 0.80 (.33-1.94) | 0.95 (0.42-2.15) |
| Relationship with CR – Child (vs. Other) | 0.86 (.86-1.99) | 1.11 (0.45-2.72) |
| **Caregiver Health Characteristics and Caregiving-related Burden** | | |
| Overall Health - Fair-Poor | 1.37 (.97-1.93) | 1.18 (0.69-2.01) |
| Current disability or physical condition | 0.99 (.64-1.52) | 0.66 (0.42-1.05) |
| Very high amounts of physical strain | 2.03 (1.23-3.35)** | 1.90 (1.00-3.63)* |
| Very high amounts of emotional stress | 1.45 (1.13-1.87)** | 1.49 (0.95-2.35) |
| Very high amounts of financial hardship | 1.64 (1.14-2.35)** | 1.14 (0.62-2.10) |
| Provides more than 10 hours of care per day | 1.41 (0.98-2.04) | 1.46 (0.90-2.37) |
| Provided care for more than 5 years | 0.87 (0.47-1.63) | 0.93 (0.50-1.74) |
| Needs someone at home nearly all/all of the time | 1.02 (.67-1.56) | 0.72 (0.41-1.26) |
| **Care Recipient Characteristics** | | |
| Age - 85 years and older | 0.85 (.54-1.33) | 0.77 (0.49-1.21) |
| Food Stamps | 0.98 (.45-2.11) | 1.25 (0.50-3.12) |
| Housing Assistance | 0.79 (.18-3.47) | 0.80 (0.16-3.94) |
| Medicaid | 0.90 (.54-1.51) | 0.91 (0.43-1.93) |
| Overall Health - Fair-Poor | 1.21 (.75-1.94) | 0.95 (0.57-1.57) |
| Diagnosed with dementia | 1.21 (.80-1.81) | 1.63 (1.01-2.61)* |

| | | |
|---|---|---|
| 3+ ADL Limitations | 0.90 (.58-1.39) | 0.81 (0.47-1.40) |
| **Utilization of NFCSP Services and Supports** | | |
| Assistance/Information to connect clients with available services | 0.59 (.34-1.05) | 0.61 (0.38-0.99)* |
| Respite care | 0.37 (.24-.57)*** | 0.23 (0.14-0.39)*** |
| Education/Training/Counseling | 0.45 (.27-.75)** | 0.31 (0.18-0.55)*** |
| Supplemental Service - Home modifications | 0.63 (.39-1.03) | 0.50 (0.26-0.96)* |
| Supplemental Service - Nutritional supplements | 0.86 (.39-1.87) | 0.81 (0.34-1.91) |
| Supplemental Service - Walkers/canes/crutches | 0.56 (.27-1.14) | 0.62 (0.25-1.49) |
| Supplemental Service - Emergency response system | 0.61 (.40-.94)* | 0.73 (0.40-1.35) |
| Supplemental Service - Specialized medical equipment | 0.95 (.57-1.58) | 0.81 (0.43-1.52) |
| Supplemental Service - Money or stipend | 0.81 (.48-1.37) | 0.84 (0.49-1.46) |
| Difficulty accessing services and supports | 2.20 (1.30-3.71)** | 1.67 (1.00-2.13)* |

*p< .05; **p< .01; ***p< .001

Data Source: 2016 responses to National Survey of Older Americans Act Participants; weighted estimates account for complex sampling strategy.

[1] Adjusted for all co-variates included in the unadjusted results.

# CHAPTER 6: DISCUSSION

This dissertation provides a current profile of NFCSP clients, differentiating between dementia and non-dementia caregivers and clients who associated with deriving limited immediate and long-term benefit from use of program services. Chapter 2 (manuscript #1) summarizes what is known about the NFCSP and concludes that limited research to date has been undertaken to evaluate the program's clients and impact. Chapter 4 (manuscript #2) summarizes the characteristics NFCSP clients and their utilization of program services, stratified by care recipient's dementia status. Dementia caregivers who used the program were more likely to report higher levels of care-related strain, stress and burdens while also more likely to receive more intensive services such as respite care and training/education/counseling. In Chapter 5 (manuscript #3), NFCSP clients who were younger, non-White or with high levels of care-related physical strain, emotional stress and financial hardship were found to be more likely to report difficulty accessing services, which may be associated with the program's impact on long-term outcomes. These three manuscripts demonstrate the NFCSP's significant role in providing support for family caregivers, but barriers may remain for younger, minority, highly strained and dementia caregivers in fully benefitting from the program.

## Summary of Findings

Although the NFCSP was launched over 15 years ago, very little has been published about the family caregivers who seek services through the program. Findings from this dissertation provide several insights about the program and provide a foundation for further analyses. First, the profile of NFCSP clients presented in Chapter 4 reveals that they are primarily White, women, daughters/daughters-in-law or caring for someone with dementia. The demographic characteristics of NFCSP clients are broadly similar to the most recent population estimates for the larger population of family caregivers of older adults in the US (Wolff et al., 2017). However, compared to these national estimates, NFCSP clients appear to care for a higher proportion of persons with dementia as well as report considerably higher amounts of physical strain, emotional stress and financial hardship. While the overall percentage of family caregivers of older adults who use caregiver support programs is quite small (Wolff et al., 2017), the program appears to serve the type of caregivers who may be the most stressed and burdened by their current care circumstances, especially among dementia caregivers.

Second, although findings from Chapter 4 indicate that most NFCSP clients rate the program highly both overall and across various specific program outcomes, disparities may exist in program benefits. Difficulty accessing services is a key measure of immediate program performance and is annually reported to Congress. Among NFCSP clients reporting difficulty accessing services, Chapter 5's results show that clients who White and older report less difficulty, while clients reporting a disability or high amounts of physical strain, emotional stress and financial hardship were more likely to report barriers in accessing support. These findings are noteworthy and complement previous research primarily attributed limited use of caregiver supports service based on personal and cultural preferences for minority caregivers (Scharlach et al., 2006; Scharlach et al., 2008; Hong, 2009; Chow et al., 2010). Previous research has found being physically and mentally overwhelmed (Robinson, Buckwalter, & Reed, 2005) and lacking the stamina and energy to research and pursue community services to help them manage their current care arrangement (Toseland et al., 2002) may explain limited use of caregiver supports among caregivers with physical disabilities and high levels of physical strain and emotional stress. Additional analyses further found that reporting difficulty accessing services may be implicated in limiting the program's benefits long-term particularly for clients reporting high amounts of caregiving-related physical strain. Findings from this dissertation indicate that additional support or outreach may be needed to overcome barriers in access to services among minority and overly strained caregivers. Further research could help determine whether difficulty accessing support is prevalent throughout the entire subgroup of clients who reported difficulty or whether additional demographic characteristics should be prioritized even within these targeted populations.

Third, use of certain key NFCSP services and supports were found to be associated with reductions in clients' reports of difficulty accessing services as well as perceptions of limited or long-term benefits for both themselves and care recipients. Chapter 4 finds that most NFCSP client received assistance and information to connect clients to available services and respite care, while less than half received education/training/counseling and supplemental services. Among these program services, receipt of assistance and information to connect clients to available services was associated with significantly less difficulty accessing program services and supports in Chapter 5.  Assistance and information, respite care and education/training/counseling were further found to be associated with lower perceptions of limited long-term benefits by NFCSP clients after using the program. The summary measure that was used to define NFCSP clients' perceptions of limited long-term benefits includes whether use of the program results in client's reporting less stress, help deal with caregiving related difficulties, more time for personal activities, easier to care for the care recipient and benefits the care recipient. Findings from these analyses suggest that use of NFCSP services and supports can provide both immediate and long-term relief for many clients adding to the current caregiving intervention literature.

Fourth, NFCSP clients assisting an older adult with dementia are more likely to report higher levels of physical strain and emotion strain and they are also more likely to receive information and assistance to connect them with available services, respite care and education/training/counseling compared with non-dementia caregivers (Chapter 4). As a potential result, study findings indicate that dementia caregivers can access program services without difficulty through NFCSP, meeting at least some of their immediate needs. However, findings also intimate that the use of such services may not benefit dementia caregivers and their care recipients long-term (Chapter 5).

## Limitations and Strengths

This dissertation has several limitations. First, the sample of NFCSP clients used cannot be generalizable to the larger population of family caregivers. As previously mentioned, the demographic characteristics of NFCSP clients are quite similar to a recent national profile of caregivers of older adults (Wolff et al, 2017). NFCSP clients, however, report higher proportions of caring for someone with dementia as well as higher levels of physical strain, emotional stress and hardship among other characteristics with a much higher proportion use caregiver support services. Although the proportion of caregivers who used support services captured in national samples is small, a comparison could be made between these caregivers and NFCSP clients to examine any further similarities and differences between the study populations.

Second, the development of the NSOAAP-CM survey questions was not constructed with the application of the organizing caregiving intervention theoretical framework in mind. Individual survey items were mapped onto the framework's four major constructs including client and care recipient characteristic, use of individual and supports and the proximal and distal outcomes related to the use of services. Results from the principal components analysis (PCA) informed both the consolidation and mapping of the survey items measuring client-reported program outcomes onto the appropriate framework constructs. Although survey items that were grouped together into three separate components hung together based on the PCA and seemed to measure similar themes, measures of internal consistency across the components were low. Low internal consistency is indicative of how limited survey items are correlated among the other items within their grouping, potentially reducing the validity of findings.

Third, these analyses may be limited by not taking into account other co-variates that may influence difficulty accessing services and supports. Due to missing data, client income was not able to be included in the analyses to gain a complete understanding of the socioeconomic characteristics of NFCSP clients and whether being low-income is associated with difficulty accessing services. Although this dissertation focused on the services received by the NFCSP clients, this study did not also take into account the use of non-NFCSP support services used by care recipients that may be available through AAAs, paid support and other caregivers support that might be available to clients.

Fourth, the NSOAAP-CM was employed as a cross-sectional survey, capturing NFCSP client experiences and responses at particular point in time. Through the organizing framework, this dissertation attempts to statistically link proximal and distal outcomes. Results from this study can only be strongly inferred. A longitudinal approach, in which the cohort is followed over time, might provide stronger evidence linking difficulty accessing services and limited long-term program benefits. Difficulty accessing services might have been just a temporary occurrence. Also, care circumstances may evolve over time resulting in changing support needs for both the caregiver and care recipients.

Although the study sample may not be generalizable to the larger family caregiver population of older adults, using the NFCSP program data offers several advantages. The survey captures a comprehensive list of variables that describes not only client and care recipient demographic and health characteristics but also their care circumstances and responsibilities. Controlling for these dynamic variables, along with measures describing use of services, strengthens the interpretations of the dissertation findings. And, use of the 2016 NSOAAP-CM survey data offers the opportunity to analyze the most recently available program data, which can offer timely insight concerning potential gaps in program coverage.

## Implications for Policies and Programs

Since the 2006 amendment was passed as part of the Older Americans Act (H.R 6197. Sec. 321. 109th Cong. (2006)), the NFCSP program has prioritized providing support and outreach for dementia caregivers, who represent approximately 60% of all clients. As a result, special considerations or dispensations have been made for dementia caregivers such as priority in the provisions of services and supports, shorter wait times, more extensive program offerings and specialized staff training (Lewin, 2016). This study hints that use of the program may be beneficial in meeting most of the immediate needs of dementia caregivers but may be limited in addressing the continuing and long-term needs of both dementia caregivers and care recipients despite their higher use of the NFCSP services that were found to be linked with increased long-term benefits. Further analysis of these dementia caregivers could drill down to assess if additional caregiver or care recipient characteristics exacerbate care circumstances and prompt a higher level of need, mitigating the effectiveness and impact of services use.

The 2006 amendment Older Americans Act (H.R 6197. Sec. 321. 109th Cong. (2006)) also mandated the use of evidenced-based programs affecting the program's provision of education/training/counseling interventions, one of the NFCSP services found to benefit clients long-term. Through this analysis, this particular service has seen a significant reduction in its use over the last 8 years, with less than half of dementia caregivers receiving and just over half of AAAs providing evidenced-based interventions. Such a reduction is potentials highlights a side-effect from both the congressional mandate, a stagnant budget and gaps in staffing (Lewin, 2016). Recent calls from IOM (NASEM, 2016) have directed recommendation towards the federal government to specifically increase funding for program such as NFCSP to implement and increase the availability evidenced-based caregiver interventions. To support sustainable implementation of these interventions, additional funding could be directed towards ensuring greater dissemination and analysis of effective interventions that have been successfully implemented through AAAs, increasing the number of dedicated staff to ensure regular availability of such interventions, and the development of core competencies and training of staff to ensure consistent delivery of proven programs (Gitlin et al, 2015). Greater availability of these evidence-based program can provide an ongoing rather than sporadic resource for dementia caregivers as the complexity of their care circumstances devolve and their needs change.

Anderson's Behavioral Model of Health Services Use has been used to identify the potential predisposing, enabling and need factors among caregivers (Scharlach et al, 2008) and care recipients (Beeber et al, 2008) which influences use of particular services and/or combination of services. Application of such a framework and subsequent analyses using NFCSP data can inform whether clients who were more likely to report difficulty accessing services because they were less likely to use certain services, notably the services that facilitates access to support and reduce client perceptions of limited long-term benefit.

Caregiver assessments enables AAA and LSPs to gain a complete picture of the responsibilities and needs of caregivers, informing the selection of specific types of support services (Dal Santo et al, 2007; Lewin, 2016; Shugrue et al, 2017). In addition to questions about client and care recipient demographics and well-being, missing from NFCSP's current standardized assessment domains are prior usage and experience accessing services and support (Mensie & Steffen, 2011; Mast, 2013; Lewin, 2016), which might infer understanding or ability to access past and future services. If previous service has been low and previous barriers identified, this may prompt focused attention by program staff to provide guidance for particular clients. Components of NFCSP's assessments and periodic re-assessments that are used to measure program outcomes also do not include questions related to clients' ability or difficulty accessing services (Lewin, 2016), which can provide more instant feedback for AAAs and LSPs as whether the program is effectively serving clients and care recipients (Tilly, Weiner, & Gould, 2014).

Future iterations of the NSOAAP-CM instrument may benefit from follow-up questions when asking whether clients experience difficulty accessing services. Further questions could include the type of difficulty or barrier that could be clarified using a set list of options based on findings from the literature. Some of these barriers may include limited English proficiency, lack of transportation to services and supports, caps on use of available services, limited service offerings from local providers, limited financial assistance, service too expensive, not offered preferred services, not enough of preferred service provided or not aware of all of the services available through the program (Whittier, Scharlach & Dal Santo,  2005; Casado, van Vulpen, and Davis., 2011; Lewin, 2016). Other potential follow-up questions could also include whether the issue was resolved based on the type of difficulty experienced and if it was resolved to their satisfaction.

## Conclusion

This study has implications for research, program administrators and policy-makers. The NFCSP is a critical program that appears to serve the nation's most vulnerable caregivers. With a constrained budget, findings from this dissertation can hopefully inform current efforts to facilitate access to current services and supports that have been shown to provide immediate and long-term benefit. While the next wave of older adults and caregivers are on horizon, it is imperative that proper service coverage is afforded to all of its clients.

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## CURRICULUM VITAE

## CHARLENE A. LIGGINS

### PERSONAL

Address: 1732 Lyman Place, Northeast
Washington, DC 20002
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Date of Birth: December 19, 1976

Citizenship: United States

### EDUCATION AND TRAINING

| | |
|---|---|
| Doctor of Public Health<br>May 2018 | Johns Hopkins University<br>Bloomberg School of Public Health<br>Department of Health Policy and Management |
| Master of Public Administration<br>May 2002 | University of South Carolina<br>Department of Government and International Studies |
| Master of Public Health<br>May 2001 | Emory University<br>Rollins School of Public Health<br>Department of Behavioral Sciences and Health Education |
| Bachelor of Arts<br>May 1999 | Washington University in Saint Louis<br>Department of Biology<br>Department of African and African-American Studies |

### PROFESSIONAL EXPERIENCE

2014 – Present
National Institute on Aging, Bethesda, MD
Division of Neuroscience
*Senior Scientific Program Analyst*
Currently lead special planning, evaluation and collaborative initiatives to support priority-setting and decision-making by Institute and Division leadership as NIH's Alzheimer's Disease (AD) and related-Dementias (ADRD) research annual budget increases from ($500M to ~$2.5B).

2008 – 2014
National Institute on Aging, Bethesda, MD
Office of Planning, Analysis and Evaluation
*Senior Scientific Program Analyst*
Led the Institute's efforts to expand and implement portfolio analyses to categorize and evaluate the performance of NIA's scientific programs and inform opportunities for collaboration with other public and private research funders (with the hope of leveraging critical resources).

2006 – 2008
National Cancer Institute, Bethesda, MD
Office of Science Planning and Assessment
*Public Health Advisor/Special Assistant to the Office Director*
Led and coordinated NCI-wide special projects and initiatives which included the Adolescent and Young Adult Oncology (AYAO) Implementation Work, the International Cancer Research Partnership (ICRP), and the "NCI's Connections" section of NCI's annual bypass budget and plan to Congress. Also served as the Office's Fellow and Intern Coordinator, mentoring and supervising masters-level and doctoral-level interns and fellows who rotated throughout the Office.

2006
National Institute of Child Health & Human Development, Bethesda, MD
Office of Communications
*Public Health Advisor*
Coordinated the *Back-to-Sleep* program, Institute's national outreach and dissemination efforts aimed at reducing fetal and infant mortality rates

2003 - 2006
United States Department of Health & Human Services, Washington, DC
Assistant Secretary's Office for Planning and Evaluation
Disability, Aging and Long-term Care Policy
*Social Science Analyst/Project Officer*
Developed and managed research projects related to disability, aging and long-term care policies including projects examining state and federal responses to nursing home and medical liability claims, the role of physician practice models and alternative providers in nursing facilities, the success of local and state-wide policy initiatives implemented to address the high rates of turnover among nursing home personnel, and the efficacy of current pre-employment screening methods for nursing home personnel. Detailed for six months to the Organization for Economic Cooperation and Development (OECD) in Paris, France, provided assistance in analyzing and describing recent disability trends among older adults residing in 12 OECD-member nations.

2002 – 2004
US Department of Health & Human Services, Washington, DC
*Presidential Management Fellow (PMF)*

Selected as PMF and assigned to rotate throughout the US Department of Health and Human Services (DHHS) including the National Cancer Institute and the Assistant Secretary's Office for Planning and Evaluation

## PUBLICATIONS AND REPORTS

Liggins, C et al (2015) Opportunities for global landscape portfolio analysis of funded research: update on the international Alzheimer's disease research portfolio (IADRP). Alzheimer's & Dementia 11: P862.

Liggins, C et al. (2014) International Alzheimer's Disease Research Portfolio (IADRP) aims to capture global Alzheimer's disease research funding. *Alzheimer's Dementia* 10:405-8.

Refolo, L, Snyder H, Liggins C, et. al. (2012) Common Alzheimer's Disease Research Ontology: Nation Institute on Aging and Alzheimer's Association collaborative project. *Alzheimer's Dementia* 8:372-375.

Liggins, C et al. (2010). Institute of Medicine's Retooling for an Aging America - National Institutes of Health (NIH)'s Investment in Developing Innovative Models of Care for Older Adults. Presented at the *2010 Gerontological Society of America Annual Conference*.

Liggins, C et al. (2010). Challenges and Opportunities in Advancing Models of Care for Older Adults: An Assessment of the National Institute on Aging's (NIA) Research Portfolio. J Am Geriatri Soc 58: 2345 - 2349.

Liggins, C et al. (2009). Retooling for an Aging America - A Response from the National Institute on Aging. Presented at the *2009 World Congress of Gerontology and Geriatrics Annual Conference.*

NIH Biennial Report Workgroup. (2009). Biennial Report of the Director, National Institutes of Health, Fiscal Years 2008 and 2009. Member of the 'Epidemiological and Longitudinal Studies' Chapter workgroup.

Liggins, C et al. (2008). A Comparative Analysis of Cancer Research Funding across International Cancer Research Partners. National Cancer Institute.

Organisation for Economic Co-operation and Development. (2007). Trends in Severe Disability Among Elderly People: Assessing Evidence in 12 OECD Countries and Future Implications. Project Consultant on behalf of HHS/ASPE.

University of Colorado. (2006). Physician Practices in Nursing Homes. Co-Project Officer – Charlene Liggins, ASPE – HHS-100-03-0028.

The Lewin Group. (2006). Ensuring a Qualified Long-Term Care Workforce: From Pre-Employment to On-the-Job Monitoring. Project Officer – Charlene Liggins, ASPE – HHS-100-03-0027.

Mathematica Policy Research, Inc. (2005). TANF Recipients as Potential Long-Term Care Workers: An Assessment of the Prospects in the District of Columbia, Illinois, Maryland, and South Carolina. Project Officer – Charlene Liggins, ASPE – HHS-100-03-0024.

Liggins, C. (2001) A Quantitative Assessment of the Attitudes, Knowledge, and Informational Needs of South Carolina Family Physicians Concerning Environmental and Occupational Health Issues. Masters Thesis. Rollins School of Public Health. Presented at the *2001 South Carolina Public Health Association Annual Conference.*

Liggins, C & Phan, D. (2001) A Utilization-based Evaluation of the Southeast Division's *Man-to-Man* Prostate Cancer Support Group Program. Collaborative Evaluation Fellowship. American Cancer Society.

Liggins, C et al. (2001) An Evaluability Assessment of the US Centers for Disease Control and Prevention's Satellite Distance Learning Program. Group Project - BSHE 530: Conduct of Evaluation Research.

Liggins, C et. al. (2000) Assessing the Ancillary Health Care Needs of Children with Cerebral Palsy and their Families Residing in Atlanta. Group Project – BSHE 524: Community Needs Assessment. Presented at the *2000 World Congress on Developmental Disabilities* on behalf of the Marcus Institute.

## COMMITTEES AND WORKGROUPS

| | |
|---|---|
| 2017 - | Co-Lead, NIH-VA Partnership: Strategic Partnership to Advance Research and Knowledge – Dementia |
| 2012 - | Member, International Alzheimer's Disease Funders' Consortium |
| 2014 - | Co-Lead, IADRP Portfolio Analysis Workgroup |
| 2013 | Co-Lead, Trans-NIH Native American/Alaska Native/Native Hawaiian Research Interest Group |
| 2013 - | Member, Trans-NIH Portfolio Analysis Special Interest Group |
| 2010 - | Lead, International Alzheimer's Disease Research Portfolio Development Workgroup |
| 2010 - 2013 | Member, NIH 'Longitudinal & Epidemiological Studies' Coding Workgroup |
| 2009 - 2013 | Lead, NIA-AoA Family Caregiving and Alzheimer's Disease Workgroup |
| 2009 - 2014 | Member, Interagency Aging and Disability Leadership Workgroup |
| 2009 - 2012 | Lead, Trans-NIA 'Longitudinal & Epidemiological Studies' Database Development Workgroup |
| 2008 - | Member, NIH Planning & Evaluation Officers Workgroup |
| 2008 - 2012 | Member, NIH Public-Private Partnership Coordination Committee |

| | |
|---|---|
| 2008 - | Member, NIH Biennial Report Workgroup, ‘Epidemiological and Longitudinal Studies’ Chapter |
| 2006 - 2008 | NCI Co-Lead, International Cancer Research Partnership |
| 2006 - 2008 | Co-Lead, NCI Adolescent and Young Adult Oncology Implementation Workgroup |
| 2006 - 2008 | Member, NCI Communications Workgroup |
| 2003 - 2006 | Member, Trans-HHS New Freedom Initiative |
| 2002 - 2003 | Co-Executive Secretary, Trans-HHS Cancer Health Disparities Progress Review Workgroup |

## TRAINING AND PROFESSIONAL DEVELOPMENT

| | |
|---|---|
| 2016 | Contract Officer’s Representative (COR) Training (NIH) |
| 2016 | Radical Collaboration (NIH) |
| 2012 | Foundations of Leadership (Johns Hopkins School of Public Health) |
| 2011 | Excellence in Government (Partnership for Public Service) |
| 2010 | Strategic Thinking: Driving Long-Term Success (Brookings Institute) |
| 2010 | Evaluating Complex Systems and Initiatives Training (NIH) |
| 2009 | Electronic Scientific Portfolio Assistant Training (NIH) |
| 2007 - 2008 | “Sherpa” Personal Executive Coaching/Training (NCI) |
| 2007 | Seminar for New Managers: Leading People (US Office of Personnel Management) |
| 2007 | Supervision: New Skills and New Challenges (HHS University) |
| 2006 | Conflict Resolution (HHS University) |
| 2006 | Effective Communications & Human Relations (Dale Carnegie) |
| 2004 | Advanced Project Officer’s Training (HHS University) |
| 2003 | Project Officer's Training (HHS University) |
| 2003 | Legislative and Congressional Operations (Georgetown University) |
| 2002 - 2004 | Presidential Management Fellowship Program (DHHS) |
| 2000 - 2001 | Collaborative Evaluation Fellowship Program (American Cancer Society) |

## HONORS AND AWARDS

| | |
|---|---|
| 2017 | NIA Director’s Award - Alzheimer’s Disease Bypass Budget |
| 2016 | Group Performance Award - Alzheimer’s Disease Bypass Budget |
| 2014 | NIA Director’s Award – Trans-NIH American Indian/Alaska Native/Native Hawaiian Research Interest Group |
| 2013 | NIH Director’s Award – Implementation of the National Alzheimer's Project Act |
| 2013 | HHS Innovates Award, Secretary’s Selection – NIA/AoA Alzheimer’s Disease Webinar Series |
| 2012 | NIA Director’s Award – Office of Planning, Analysis & Evaluation |
| 2010 | NIA Director’s Award Honorable Mention – Development of the ‘Common Alzheimer’s Disease Research Ontology’ |

| | |
|---|---|
| 2010 | NIA Director’s Award - NIA’s Research on Models of Care for Older Adults/Portfolio Analysis |
| 2009 | On-The-Spot Award - OPAE Combined Federal Campaign Team Leader - Raised $10,000 |
| 2009 | On-The-Spot Award – NIA Models of Care Portfolio Analysis |
| 2008 | NIA Director’s Award – Trans-NIH Biennial Report |
| 2004 | On-The-Spot Award - ASPE Combined Federal Campaign Team Leader - Raised $55,000 |
| 2003 | On-The-Spot Award - Secretarial Town Hall Meeting on Family Caregiving |