

A Study on Family Caregiver Support Programs in the U.S.A.: The Case of the State of Georgia

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Abstract

This is a descriptive study that introduces programs that support family caregivers looking after the elderly, by focusing on the case of Georgia, in the United States. The U.S. is one of the few countries that support family caregivers by law. In this study, we focus on the evidence-based interventions implemented through the Alzheimer's Disease Supportive Services Program (ADSSP), a federal policy that complements the National Family Caregiver Support Program (NFCSP). Our findings show that one-on-one evidence-based programs (EBPs) for family caregivers are both economical and effective in assisting caregivers. In our discussion, we highlight how the implementation of the latest EBPs can build an infrastructure to support family caregivers. ADSSP funding is useful as it constructs a caregiver support through the implementation of programs in the local community. The result is the creation of a well-coordinated division of labor among government agencies, academia and NGOs, which produces a synergetic effect in funding, research and development, translation and implementation of programs, and staff training. We conclude that the implementation of EBPs funded by the government is a useful reference for Korea and other rapidly aging countries, if we are to create an infrastructure for caregiver support, which can effectively prevent a crisis in caregiving.

Keywords

family caregivers, family caregiver support programs, NFCSP, ADSSP, evidence-based programs, U.S.A.

Introduction

The United States is undergoing a dramatic demographic transition in aging. The U.S.'s share of the population aged over 65 in 2010 was 13%, projected to increase to 21% in 2050 (OECD). The rapid growth of the elderly segment poses serious economic, social, and political challenges for this nation in the area of caregiving. Referred to as the "caregiving crisis" (Rosalyann Carter Institute for Caregiving, 2010), this challenge is understood as a consequence of the demographic imbalance between caregivers and care-receivers. It also refers to the lack of awareness and readiness, at both the individual and social level, to provide adequate care.

To counter social costs in caregiving, the U.S. has encouraged in-home care to delay placement

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in nursing homes, which accounts for a high prevalence of in-home caregiving by family members or neighbors. A study notes that seventy-five percent of adults over 65 years of age, with at least one disability, were being cared for solely by a family member (Choi, 2009). This arrangement found family caregivers under considerable physical, emotional and financial strain (Administration on Aging, 2016; Vitaliano, Young & Zhang, 2004). Ultimately, the caregiving crisis becomes the trigger for the “caregiver’s crisis,” the physical, psychological and financial challenges that individual caregivers face as they engage in the overwhelming task of caregiving with little support.

In 2000, the U.S. Congress passed the National Family Caregiver Support Program (NFCSP) under the Older Americans Act (OAA) to assist family caregivers by providing respite and support programs to alleviate stress and burden. Another support program, the Alzheimer’s Disease Supportive Services Program (ADSSP), was enacted through the Public Health Services Act (Art. 398) in 2009, to specifically assist family members caring for Alzheimer patients. The U.S., along with Great Britain, is one of the few countries that support family caregivers exclusively by law (Cho, 2008; Kang, 2009; Kim & Hong, 2007). These policies have led to an increase in caregiver awareness and self-identification, caregiver support research and program development by academics and advocate groups, and a rise in the implementation of evidence-based programs (EBPs) at the community level.

Korea’s demographic transition in aging is more pronounced than the U.S. Korea’s population aged 65 years and over was 11% of the total population in 2010, and is projected to increase to 37%, the world’s second highest rate after Japan, in 2050 (OECD). While Korea faces the same challenges as the U.S. in caregiving, it has adopted a different policy stance in meeting these challenges. In Korea, caregiving has taken a social turn as the government adopted a long-term care insurance policy in 2008. However, many scholars have pointed out that the socialization of care has overshadowed the prominent role of family members in our care system (Kang, 2009; Kim & Woo, 2013; Choi, 2009). Research shows that the adoption of a long-term care insurance program did not necessarily lead to a decrease in family caregiving. Due to strict conditions that limit eligibility, recipients who receive full benefits comprise only 6% of the elderly population (National

Health Insurance Service, 2014). This suggests that a much larger number of elderly are being cared for by informal caregivers. Of the 81.7% of the elderly who were receiving care, 91.9% were looked after by a family member (although not exclusively) (Jung *et al.*, 2014). It should also be noted that Korea has a culture that emphasizes family obligations as a moral duty (Kim & Moreno, 2012), which may deter adult children from putting their parents in nursing homes and to be openly vocal about the hardships they may encounter while caring for a loved one. Nonetheless, Korean caregivers equally feel the strain and burden from the caregiving process. Elderly family caregivers are reported to have lower satisfaction in quality of life compared to non-caregivers, and the physical and mental health of adult children caring for their parents are reported to be ‘poor’ to ‘very bad’, with low satisfaction on quality of life due to stress (Choi, 2009).

At present, Korea does not have a comprehensive support policy for family caregivers. The City of Seoul has recently launched a family caregiver group program for dementia patient caregivers, as part of the government’s “War against Dementia” campaign (Seoul Metropolitan Center for Dementia, 2015). However, this effort is not part of a wider national policy that assists family caregivers at large. Caregiver awareness and self-identification remain low, efforts to organize and support caregivers at the non-governmental level and community remain scarce, and whereas there is considerable research on family caregiver stress and burn-out, there are few explorations on intervention programs, Korean and otherwise, that can alleviate the burden of caregivers. Many studies have emphasized the need for a public family caregiver support program in Korea (Jang *et al.*, 2005; Kang, 2009; Kim & Woo, 2013), but only a few have explored their possible contents and scope, the wider system in which they operate, and the conditions that make their implementation successful.

This study was borne from the concern that Korea will soon face, if it does not already, a caregiving crisis that will assert itself through a caregivers’ crisis. We concur with previous studies that have advocated for a government-funded family caregiver support program in Korea. But exactly what will the support program consist of, and in what capacity will such programs be offered? We believe that, with a longer history of family caregiver support, the American case can provide a reference point for the

development of a family caregiver support program in Korea. As mentioned above, the policy concerning long-term care adopted by Korea and the U.S. have fundamental differences. The U.S. supports family caregivers because it is in the state's interest to keep caregiving within the family and out of costly nursing homes. The path Korea has adopted is different in that it has chosen to provide services that will eventually replace family caregiving. Despite these differences, there are substantial reasons why the U.S.'s family caregiver support system deserves closer scrutiny. First, we should note that Korea's long-term care insurance does not comprehensively fulfill our nation's demand for care. Second, it is still the family that is responsible and in charge of caregiving, disrespectful of whether or not the care-recipient is a beneficiary of our long-term care system. Hence, despite the disparities in the context and orientation of elderly care policy of the two countries, it is useful to assess the types of policies and systems available to complement our own long-term care policy. Equally, it is important to note their usefulness and limitations.

There have been previous studies published in Korea that introduce family caregiver support in the U.S. (Kim & Woo, 2013; Jang *et al.*, 2005). Specifically, Kim & Woo discuss the U.S.'s official family caregiver support policy, the National Family Caregiver Support Program, with Korea's long-term care insurance policy, at the national level from a comparative perspective (2013). Our study seeks to expand this discussion by incorporating family caregiver support policy as practiced and executed at the state and local community level, to shed light on the specific practice measures that are delivered to family caregivers in need of support.

It is in this context that this study seeks to present and analyze: 1) the contents of the programs and scope (reach) of family caregiver support that are available at the state and local level; and 2) the infrastructure and processes that enable implementation of family caregiver support programs in the U.S.; with special attention to evidence-based interventions, which have proliferated rapidly in recent years but received little attention. By identifying the elements that create a sustainable support system for family caregivers, we hope to present a useful reference in establishing an effective family caregiver support system in Korea.

Methods

In this study, we used the case of the State of Georgia to look into family caregiver support delivered at the local level. The reasons behind this choice are as follows. First, ranking 24th in size among the 50 states and eighth in terms of population (Wikipedia, 2016), Georgia has a concentrated population in the Metropolitan Area of Atlanta, but also a rural population spread throughout the state, with a higher ratio of the elderly in rural areas (Greene *et al.*, 2011), which is similar to the geographical distribution of Korean demographics. Second, although the proportion of the elderly population (aged 60+) in Georgia is not particularly high compared to other states, the increase rate of this population ranks fifth in the country. It is projected that Georgia's elderly population will increase 65% between 2010 and 2030, from 1,528,041 to 2,533,710 (Georgia Division of Aging Services, 2008; 2011). The case of Georgia is an example of how the state government engages with an oncoming caregiving crisis. Third, Georgia is home to the Rosalynn Carter Institute for Caregiving (RCI), a research and practice think-tank specializing in caregiver issues. The RCI has provided translation and implementation of caregiver support programs developed by researchers nationwide. As a recipient of various ADSSP grants, the RCI has also administered several intervention programs for family caregivers in Georgia. Georgia thus provides a fertile ground to explore how federal incentives for family caregiver support are enacted at the state and local level, and conversely how the state government and local communities proactively engage the federal support system.

Our study employed a two-step method to adequately answer our research questions. First, we conducted a thorough literature review of both U.S. federal and state government reports, Korean government think-tank reports and statistics, as well as academic journals and monographs on family caregiver support, in order to map the basic skeleton of the family caregiver support system at the federal, state and local levels. By first sifting through the federal and state reports on family caregiver support programs available on official websites, we identified the programs that were implemented through the NFCSP and ADSSP, respectively. Once

Table 1. Research methods by type and sources

Method	Type	Sources
Literature review	- U.S. federal and state govt. plans and reports on family caregiver support - Korean govt. plans and reports on family caregiver support	- Administration on Aging - Administration for Community Living - Georgia Division of Aging Services - Seoul Metropolitan Center for Dementia
	Think-tanks	- National Caregiver Alliance & National Center on Caregiving - AARP Public Policy Institute - Rosalynn Carter Institute for Caregiving - RTI International
	Monographs and articles on adopted caregiver support programs in Georgia (REACH II, RCI-REACH, TCare, BRI Care Consultation, NYUCI, Powerful Tools)	- RCI Caregiving Series - Journal articles - support program websites
On-site fieldwork	Focus-group interview & semi-structured interview	- Coastal Georgia AAA (GA-REACH) - Southwest Georgia AAA (Powerful Tools) - Rosalynn Carter Institute for Caregiving - Kuro Center for Dementia (Seoul)

the programs were identified, we conducted a search on Google Scholar and Google, using the title of the intervention programs (i.e., REACH II) to gather information on the respective programs, their methods of delivery, costs and efficacy.

After identifying the contents and scope of programs supported by the federal and state government, our study was complemented by qualitative research based on fieldwork in Georgia between 2012 and 2014. Each visit was organized around 7-10 days. To get a sense of how the programs were chosen and delivered, and to cross-check the data collected through our literature review, we conducted on-site interviews with personnel at two Area Agencies on Aging (AAA), the “gateway” for elderly services at the local community level, and the staff at the Rosalynn Carter Institute for Caregiving (RCI), a recipient of ADSSP grants, which was at the time also the service provider conducting family caregiver interventions. Table 1 shows a summary of the research methods employed in this study.

Context

Family caregiver support policy in the U.S.: NFCSP and ADSSP

In 2000, the NFCSP became a law under the Older Americans’ Act (OAA), thereby providing a legal basis for family members caring for an elderly person, at the federal level. The NFCSP

requires states to develop and deliver programs that address the need of caregivers, and provides funding for them based on the number of individuals over 70 years of age in each state. Its objective lies in reducing the burden of family caregivers and preventing burnout, so as to prolong in-home care to prevent and delay placement in a nursing home. As such, the NFCSP responds to the needs of both the government and families: cutting costs in providing care for the elderly, while responding to families’ aversion and resistance to nursing home placement.

The services funded by the NFCSP fall into the following five categories: 1) information about available services and support; 2) assistance in accessing available services; 3) counseling, training, and organizing support groups to help family caregivers in their role of caregiving; 4) respite care for family caregivers to provide temporary relief from caregiving; and 5) supplemental services to address specific caregiver needs (Administration on Aging, 2016).

In 2014, the budget for the NFCSP was \$145 million, which comprised 7.7% of the total AOA budget (Fox-Grage & Ujvari, 2014). Many have noted that this sum falls short in meeting the needs of an increasing number of caregivers (Davis, Gilliss & Harper, 2011; Fox-Grage & Ujvari, 2014), considering that the net value of family caregiving in the U.S. amounts to \$300 billion (Family Caregiver Alliance & National Center on Caregiving, 2015).

Adopted in 2009 through the Public Health Service Act (Art. 398), ADSSP seeks to assist families with dementia patients by providing a support service system to delay institutionalization. As a policy designed to ‘enhance’ the NFCSP, it provides dementia-capability grants and evidence-based grants to states that demonstrate the capacity to implement them. Because the program originates from a different legal basis, and hence a different budget, ADSSP has mostly been overlooked in the family caregiver support literature. Dementia-capability grants support grantees in improving state service delivery systems, while evidence-based grants are used in translating and implementing interventions that have been proven to improve caregivers’ conditions after adapting them to the community. The funding of EBPs is significant, as this practice entails years of research and development, as well as a well-trained professional staff to deliver them. The budget size of the ADSSP, like the NFCSP, is not grand. The Administration for Community Living (ACL), of the U.S. Department of Health and Human Services, has allocated 3.7 to 4 million dollars per year since 2012, and reports that during 2008-2014, approximately 47,000 persons with dementia and their family caregivers have benefited from ADSSP services. Because ADSSP operates on a grant basis, only 17 states, including the state of Georgia, are presently listed as recipients (Link, 2015-16).

Family caregiver support delivery system

The family caregiver support delivery system at the federal, state, and local level is shown in Fig. 1. Public funding for supporting family caregivers is allocated by the U.S. Department of

Health and Human Services. Within this administering body, ACL operates various support systems to different welfare recipients. The U.S. Administration on Aging (AOA) is a division within the ACL that is in charge of elderly affairs, and also manages family caregiver support programs, such as the NFCSP and ADSSP.

The AOA is the organ that channels the federal funds to the state government. Each state government has its own department or division that administers the elderly and their caregivers. In Georgia, the Division on Aging (DAS) is in charge of supporting family caregivers to implement NFCSP and ADSSP programs. It does this through the Area Agencies on Aging (AAAs), local agencies that reach out and offer services for the elderly and their caregivers at the community level. AAAs are the last receiving end of federal funds, and the sites where programs are offered or managed. AAAs are sometimes contracted out to non-profit organizations (NGOs), instead of being a public organization *per se*, and oftentimes the DAS or AAAs will work with local NGOs, such as the Alzheimer’s Association (AA) or the Rosalynn Carter Institute for Caregiving (RCI) as joint grantees when developing and/or implementing programs. AOA has made it a priority that local AAAs act as the gateway to all services pertaining to the elderly, to avoid confusion and maximize service access. Each AAA has an Aging and Disability Resource Center, which ensures that no consumer is shown “the wrong door” to available resources.

Family caregiver support in the State of Georgia

According to the Family Caregiver Alliance & National Center on Caregiving, the number of family caregivers attending to the

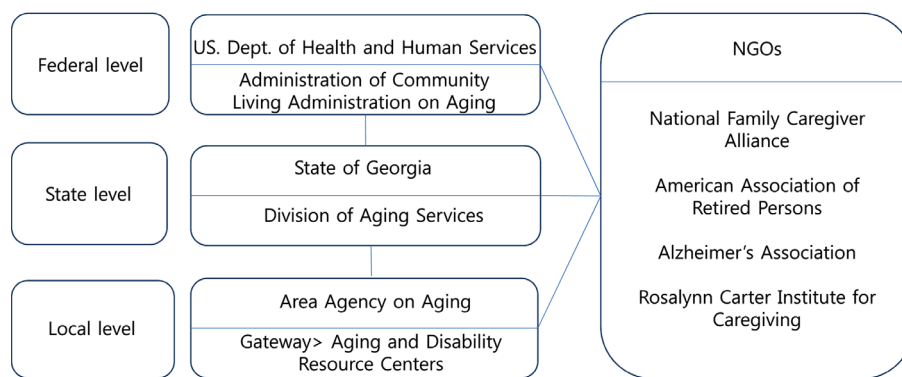


Fig. 1. Family Caregiver Support Delivery System in the U.S.A., from Federal to Local Level

elderly is estimated to be about 550,000 (2015). Georgia has 12 AAAs operating in the state, and in 2014 was the 11th highest recipient of NFCSP funding among the 50 states and two U.S. territories (Administration for Community Living AGID, 2014).

According to the AOA, the NFCSP budget size allocated to Georgia was \$3,547,261 in 2012, and \$3,418,391 in 2013 (Administration for Community Living AGID, 2014). The ACL stipulates that the state government has to match 25% of this budget. We found no reference to the specific budget size of caregiver support in state government reports, but if we calculate the budget allocated by the AOA and add the matching fund of 25%, it can be estimated that Georgia’s baseline budget for NFCSP roughly amounts to \$4 million annually.

We were not able to find data on the amount of ADSSP grants in Georgia. We know, however, that ACL has allocated 3.7 to 4 million dollars per year to ADSSP since 2012 (Link, 2015-16). In 2014, it was reported that the ACL gave out 60 grants, serving a total of 28,227 persons, split evenly by dementia patients and caregivers (Gould *et al.*, 2014). A rough estimation of funds allocated to each grant would be \$66,000 annually, if divided equally. Georgia was the recipient of 6 grants to implement EBPs for caregivers between 2008 and 2015.

Findings

Georgia DAS has integrated NFCSP and ADSSP funds to provide service for family caregivers through the AAAs. The Annual Reports of the DAS tabulates the scope of family caregiver support not by amount of budget allocated, but by persons served, often in duplicates. Here, we present the types of family caregiver support services funded by the NFCSP and ADSSP, respectively. We have included a brief description of the programs and how many caregivers have received each specific services, as documented in official state reports. We present a more detailed description on the EBPs funded through the ADSSP, as these programs have not been widely introduced in previous studies in Korea. Lastly, we provide an analysis on how the implementation of evidence-based intervention programs create a working infrastructure that supports family caregivers.

Table 2. Number of Recipients of Family Caregiver Support by Type of Services in Georgia (2013-14)

Type of service	2013	2014	
	Caregivers served	Caregivers served	
Adult day care and respite	3,520	3,098	
Consumer-directed care	Homemaker and personal care	4,521	4,501
	Material aid	5,076	3,358
Case management and counseling	329	6,160	
Telephone reassurance	563	471	

Source: Georgia DAS, 2013; 2014

NFCSP-funded services in Georgia

The main services funded by the NFCSP in Georgia were respite care (including adult day-care), consumer-directed care, and telephone reassurance calls. What follows is a description of each services and the number of family caregivers served in the years 2013 and 2014. A summary of these services is shown in Table 2.

Respite care

DAS reports that one of the service highest on the list of caregivers’ needs is respite care (Georgia Division of Aging Services, 2011). Respite care refers to temporary institutional care of a dependent elderly, thereby providing relief for their usual caregivers. Recently, DAS has merged the two categories of regular adult-day care and respite care. Taken together, the caregivers served in the respite category were 3,520 and 3,098 for the years 2013 and 2014, respectively (Georgia Division of Aging Services, 2013; 2014).

Consumer-directed care

In 2001, DAS was awarded a three year NFCSP innovation grant to develop and evaluate a self-directed voucher care project for the non-Medicaid older population in rural areas of the state. The voucher allowed consumers to hire a neighbor, friend or licensed agency to provide personal care or perform errands, and also the purchase of consumable supplies, such as nutrition supplements and incontinence products (Greene *et al.*, 2011). By July 2007, there were four consumer-directed programs for family caregivers in 59 counties, serving 424 caregivers. Additional

sites have been added since and now this program is provided throughout the state. This program provided up to \$1,200 annually for personal care services and an additional \$600 for consumable supplies, per person.

In 2013, 4,521 caregivers received personal care vouchers and 5,076 received material aid for consumable supplies. In 2014, caregivers receiving personal care vouchers was similar to similar to 2013, benefiting 4,501 caregivers, but the number receiving material aid dropped to 3,358 caregivers (Georgia Division of Aging Services, 2013; 2014).

Telephone reassurance calls

This is a service where trained volunteers call persons with dementia who live alone, and their caregivers. The program was developed by representatives from 12 AAAs, the Alzheimer’s Association, and adult protective services to provide assistance to those living in isolated rural areas. In 2013, calls were made to over 563 caregivers, and 471 caregivers in 2014. A notable aspect of this program is that volunteers for this program were selected from a pool of early dementia patients (Georgia Division of Aging Services, 2013; 2014). The reason behind this choice was that these patients knew first-hand the frustrations and difficulties faced by dementia patients and their caregivers. Despite the risks involved

in making such a decision, the program has been reported to be successful and is on-going.

ADSSP-funded EBPs for Georgia family caregivers

Evidence-based interventions are programs whose efficacy have been proven to have statistically significant outcomes through randomized controlled trials, with results published in peer-reviewed journals. In the past few years, evidence-based interventions for caregivers have been honed for implementation in local communities. With proven results in terms of efficacy in improving caregivers’ health, AOA began giving out ADSSP grants for implementing EBPs in local communities.

Between the years 2008 to 2015, Georgia has received 6 evidence-based grants for dementia family caregivers, in collaboration with local caregiver research and advocacy institutions such as the RCI. Table 3 shows EBPs implemented in Georgia from 2008 to 2015.

GA-REACH II and GA-REACH Coastal Project

REACH II is a program originally developed by the Veterans’ Association for family caregivers tending to veterans with dementia, lasting 6 months with at least 12 sessions. As an intensive immersive 1:1 program in which an interventionist makes 9 in-home visits and 3 telephone updates, REACH’s objectives

Table 3. Evidence-based Programs for Family Caregivers Implemented in Georgia (2008-2015)

Evidence-based programs	Support year	Families served	Intervention method	Other
GA REACH-II	2008–2011	85 families	Home-visit	program costs (caregiver/per day): \$7
	2011–2015	150 families	Telephone	
GA REACH-Coastal Project	2010–2013	150 families	Home-visit Telephone	
GA NYUCI	2009–2013	150 spouse caregivers	Individual and family counseling Support group	Specifically targeting GA’s African American families
GA Care Consultation	2010–2013	600 families in 6 AAAs	Telephone	program costs (caregiver/per day): \$2
T-CARE	2010–2015	2010: 4 AAAs 2011: 12 AAAs	Telephone and internet	2011: trained 60 care managers
Powerful Tools for Caregivers	2010–2015	500 caregivers in 12 AAAs annually	On-site group program	recipients not limited to dementia patient caregivers

Source: Georgia DAS, 2011; 2015 (State Plan)
 Georgia DAS, 2010; 2011; 2012; 2013; 2014 (Just the Facts)
 Rosalynn Carter Institute for Caregiving 2016a; 2016b

are to bring: 1) improvement in overall caregiver health and depression; 2) reductions in feelings of burden from caregiving; 3) improvement in caregiver management of troubling behaviors of the care recipient; and 4) delay in institutionalization. The program has been proven to bring statistically significant improvements in depression and burden (Easom, Alston & Coleman, 2013).

Renamed GA-REACH II, the program was implemented in collaboration with the RCI. During the period of 2008-2011, GA REACH II was implemented in 11 counties, serving 85 caregivers, and in 2011-2015, serving 150 caregivers. An off-shoot of the REACH program was implemented in the Coastal GA AAA from 2010-2013, serving 150 families. Since a pre-post research design is embedded in the program during implementation, the outcome of the intervention is measured at the end of each program. Results showed that caregivers reported decreased depression, decreased burden, improved caregiver health, and decreased behavioral problems of care receivers. Caregivers also expressed feeling empowered and more capable of addressing the needs of care recipients (Easom, Alston & Coleman, 2013; Georgia Division of Aging Services, 2011).

A significant aspect of this program, like other EBPs, is that it achieves both improvements in caregiver health and cost effectiveness. Much of the costs derive from training and educating the interventionists, their salaries and travel costs to go to the home of the caregiver. The estimated cost for admitting and implementing the program to one caregiver was reported to be \$7 per day. Considering that the program lasts 6 months, the total costs incurred for one caregiver by one interventionist would be \$4,410. In comparison, the cost per day in a long term care facility is estimated at \$215 per semi-private room, inclusive of lodging and meals, or \$39,237 for 6 months. The program is thus considered to be economical (Easom, Alston & Coleman, 2013).

Georgia NYUCI Family Support Program

The NYUCI is a 6-session counseling program that supports caregivers through an initial caregiver counseling meeting, 4 family sessions, and a subsequent caregiver counseling meeting, with additional time for assessments, phone calls information and support group participation. The program's objectives are to reduce depression and stress, and improve caregiver health. In Georgia, the

program showed statistically significant improvements in measures of caregiver burden, caregiver satisfaction with social network, and the desire to institutionalize care recipients for caregivers who were considering institutionalization prior to the intervention (Gould *et al.*, 2014). Lately, the program has been developed into an online package, making it possible for interventionists and caregivers to connect through the computer without having to travel distances.

In Georgia, the program was implemented with the collaboration of RCI in two AAAs, serving 150 caregivers from 2009-2013, and again for the same number of caregivers in 2011-2015. The program mostly targeted to low-income African-American families in Georgia, who have little access to services and information pertaining to dementia (Georgia Division of Aging Services, 2008, 2011; Rosalynn Carter Institute for Caregiving, 2016). Although we were unable to find published records pertaining to the costs involved in the implementation of the program, a study by Long *et al.* suggests that the NYUCI can save the State of Minnesota \$996 million in direct care costs between 2010 and 2025 (2014). The training, education and salary of care counselors, and travel distances are likely to incur the majority of expenses in implementing this program, which should not be drastically different from the costs of the GA REACH program. Delivering this program online is bound to bring down such costs, allowing the state to provide the same services to a larger number of family caregivers.

GA Care Consultation

Developed by the Benjamin Rose Institute on Aging, Care Consultation (BRI CC) is a *telephone-based*, empowerment intervention that helps both family caregivers and care receivers by giving out information about health problems and available resources, while providing emotional support. This program is different from other interventions in that it is based on an empowerment philosophy: a care consultant, who acts as a coach, ensures that caregivers practice the necessary "action steps" to solve their problems. BRI CC operates on a unique database software program, which is manned by the care consultant as he/she records the status of action steps of their clients. This program has been shown to be effective in reducing care-related strain and increasing satisfaction with health care services. Specifically for

caregivers, it showed decreased symptoms of caregiver depression, reduced caregiver stress and burnout, and reduced isolation strain and improved access to information (Bass *et al.*, 2015-16; Rosalynn Carter Institute for Caregiving, 2016).

This program was conducted in 6 AAAs in collaboration with RCI, serving 600 families from 2010-2013. The cost incurred by one caregiver per day was estimated to be \$2, mainly to cover costs for the care consultants, supervisors, training and software. Since the intervention is done by telephone, the program does not incur travel expenses and costs remain relatively low.

T-CARE

Standing for Tailored Caregiver Assessment and Referral System, T-CARE guides care managers through an assessment and care planning process that examines the care context to identify sources of stress of family caregivers. Care managers measure caregiver burden, depression and identity discrepancy, and create strategies to encourage caregivers to enact on their decision through the Plan-Do-Check-Act plan. T-CARE has been proven to reduce caregiver stress and clinical depression and increase the positive feelings caregivers have about caregiving (TCare, 2016; Georgia Division of Aging Services, 2011; 2013).

In Georgia, T-CARE has been implemented from 2010-2015, in 4 AAAs in 2010, and 12 AAAs in 2011 (Georgia Division of Aging Services, 2011). The number of caregivers served has not been documented.

Powerful Tools for Caregivers

Powerful Tools for Caregivers is an on-site, group program led by a certified class leader, held over 6 weekly classes to educate the caregiver in self-care tools: 1) to reduce personal stress; 2) change negative self-talk; 3) communicate one's needs to family members and healthcare/service providers; 4) communicate more effectively in challenging situations; 5) recognize the messages in their emotions and deal with difficult feelings; and 6) make caregiving decisions that are tough and difficult. The evidence shows that the programs improves self-care behaviors (increase in exercise, use of relaxation techniques, and medical check-ups); management of emotions (reduced guilt, anger and depression); self-efficacy (increased confidence in coping with caregiving demands); and use

of community resources (Kuhn, Fulton, & Edelman, 2003; Georgia Division of Aging Services, 2014).

This program has been implemented in Georgia from 2010-2015, serving about 500 caregivers in 12 AAAs annually. Of the EBPs implemented in Georgia, this is the only group program that is held on-site. In our interviews with AAA staff, we found that participation in this program led caregivers to organize their own support groups. Unlike the other EBPs funded by ADSSP, Powerful Tools does not specifically target dementia patient family caregivers. The program has also been translated into Spanish and Korean, which makes it one of the few programs that can be implemented in different ethnic communities (Georgia Division of Aging Services, 2013).

Implementation of EBPs as means to create support infrastructure

Our findings show that despite the acknowledgment for the need to support caregivers and legislation of the NFCSP, public funding to assist family caregivers remains very low. State governments have to match 25% of federal funding for family caregiver support, and yet in the case of Georgia, family caregiver support comprises less than 7% of the budget allocated to aging services. As seen in Table 2, only a fraction of caregivers in Georgia were receiving support in respite and consumer-directed care. We can see how narrow the range of support is, if we consider that only about 4,000 persons from an estimated 550,000 family caregivers, received respite care service.

It is probably due to this limitation that the ADSSP was adopted. As a policy that complements the NFCSP, ADSSP funds are meant to serve family caregivers in the high-risk group— those caring for dementia patients. But two limitations should be noted. First, this program only benefits family caregivers of dementia patients, excluding caregivers tending to the elderly with chronic illnesses and other serious conditions, such as cancer. The second limitation is that ADSSP funds are *grant-based*, and not universal. Only successful applicants receive the money, hence the divergence of ADSSP support across states. Georgia presently is a recipient of both dementia capability grants and evidence-based practices grants. In the former category, it has installed online educational webinars to train professionals on dementia (not directly supporting

caregivers), and in the latter, we have seen that there were at least 6 EBPs being practiced in various communities across the state in the past ten years. What enabled Georgia's DAS to successfully receive these grants? A common factor found in the implementation of both programs is the collaboration of DAS with the Rosalynn Carter Institute for Caregiving and Alzheimer's Association, among others. Although one cannot say with certainty that this was *the* most decisive factor, the presence and collaboration of non-governmental organizations with a long history and development within the local community, that has expertise and a commitment to caregiver support, seem important in securing ADSSP grants.

Despite the fact that family caregiver support funds are limited, DAS reports show that they are used where needs are greatest: for respite care. This service is important for caregivers as physical and emotional exhaustion are the most highly reported challenge they face. The other support category that is reaching many caregivers is consumer-directed care, which provides cash for services and purchase of supplies. This is a flexible approach to meet the needs of caregivers, which can vary according to their situations. The issue, then, pertains not to the contents of the programs, but rather to the scope and reach of such programs. It is a matter of increasing funding resources, rather than not having the right types of support services.

Because lack of funding is such a crucial issue in family caregiver support, the fact that recently implemented EBPs are very economical, is extremely significant. We won't discuss the efficacy of EBPs at length here, since being *evidence-based*, their outcomes have been statistically proven. Our findings show that GA REACH II and BRI CC both cost little to provide high-quality support for family caregivers. Although we have to keep in mind that the implementation expenses do not include research and development for the programs, the comparatively low cost of these programs means that more caregivers can be served within a limited budget. This is important, as it shows that supporting family caregivers is not an expensive task, especially considering how much in-home caregiving contributes to cutting costs.

The low costs do not translate into impersonal and low-quality service. On the contrary, our findings show that most EBPs now employ one-on-one personal intervention rather than serving caregivers in a group setting. Of the programs in Georgia, only

Powerful Tools is an on-site group program to which the caregiver has to make the time and effort to attend. There is also a shift in content. While the programs do have elements of emotional support and education on methods of coping, most involve coaching the caregiver in problem-solving, communication methods with family and care receivers, stress management, and empowerment. The programs emphasize cognitive restructuring in the caregiver rather than simply providing emotional comfort.

GA REACH II, for example, is a one-on-one program in which a certified (licensed, hence formally trained) interventionist coaches and assists caregivers through a coaching process to deal with the physical and emotional challenges they encounter during the caregiving process. Since the program can be implemented in the patient's/caregiver's home, the interventionist has first-hand contact and knowledge of the family situation, and by forming rapport, can be very effective in helping the caregiver feel less isolated and find solutions to his/her problems. It is important that the caregiver does not have to leave home, as was the case when programs mostly involved on-site education and support group meetings. Being evidence-based, the training of interventionists also follows a strict protocol, the result being the formation of a professional group of caregiver support specialists. The low costs also make the programs more likely to be funded in the future to ensure sustainability of the programs in the community.

The development of EBPs with innovative methods of service delivery is also noteworthy. BRI Care Consultation, for example, has care consultants call the caregivers by telephone. Keeping a one-on-one tracking, monitoring and logging system that assists caregivers over telephone calls is an efficient way to assist caregivers and meet their unique needs. Also, the action-plan process employed in this program encourages the caregiver to act on the decisions he/she made with the care consultant. This makes the caregiver not a mere passive "recipient" of services, but rather emphasizes the will and capacity of the caregiver as an active agency. In other words, the care consultant does not provide easy, ready-made answers to the caregiver's problems, but rather acts as a guide to keep the caregiver in the path to enact his/her own resolutions. Also, since care consultants do not have to travel distances, the program is economical. As in the case of REACH, the training and education for care consultants follows a protocol,

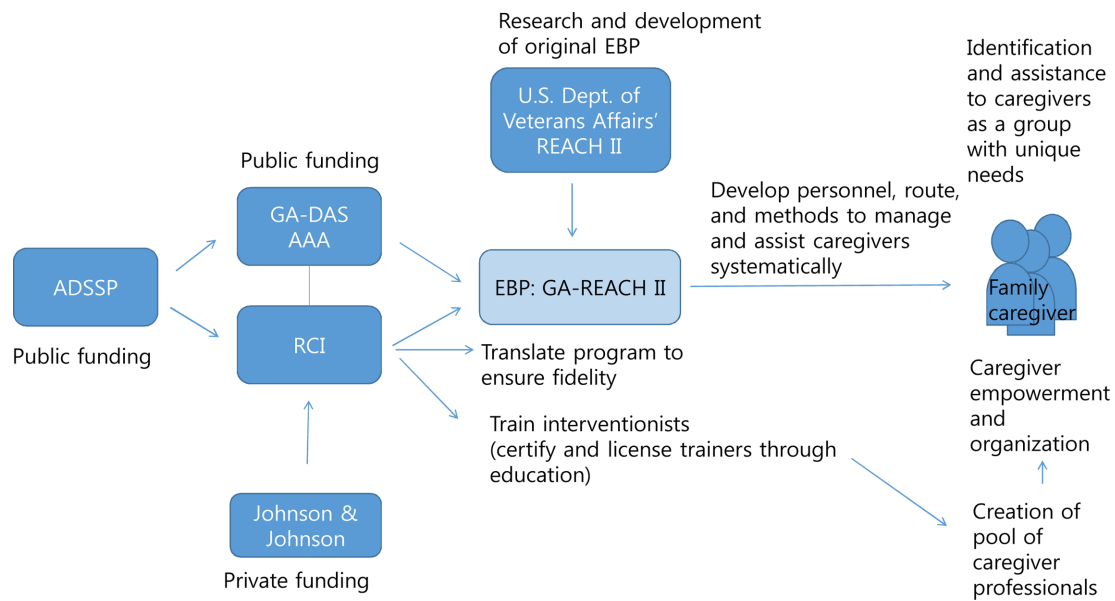


Fig. 2. Family Caregiver Support Infrastructure Created through Implementation of EBP

and only licensed interventionists can provide assistance, thereby assuring the quality of the intervention.

The proliferation of EBPs in local communities is significant because they are effective in reducing burden, stress and depression in individual family caregivers, and also because the process empowers them and make them more confident in the decisions they make (Link, 2015-16; Bass *et al.*, 2015-16; Easom, Alston & Coleman, 2013). In the long run, EBPs contribute in delaying nursing home placement (Georgia Division of Aging Services, 2012), the objective of both the NFCSP and ADSSP. We find, however, that the implementation of EBPs also has a more important significance in the larger scheme of family caregiver support as a system. Our findings suggest that the implementation of EBPs at the community level cannot be borne from the fruits of labor of only one entity. The complexity and technicality of EBPs demand that they cannot simply be taken from university experimental laboratories to the field. In the case of Georgia, we found a division of labor among various parties that converged into a public-private collaboration that enabled successful implementation of programs. We have reconstructed the infrastructure that enables the practice of an EBP in the field with the case of GA-REACH II, in Fig. 2.

The first step is the creation of an EBP by a research or

University institution, which we call the ‘research and development process.’ This process in itself requires a significant amount of funding and time. It is constantly revised to accommodate new findings to make the programs more effective and significant across populations. GA-REACH, for example, is an off-shoot of the REACH program that was developed almost a decade ago at the U.S Dept. of Veterans Affairs to assist veterans with dementia.

To bring such programs to the community requires developing implementation protocols and training personnel who faithfully deliver the programs within the parameters of their original intentions and formats. State governments or local AAAs can take up this task, but it requires a more specialized understanding of the programs, which administrators may lack. Non-governmental research and practice organizations, advocate organizations can fill the gap. In this case, it was undertaken by the RCI, a caregiving research, practice, and advocacy think-tank based in Georgia, which has been working on behalf of caregivers since 1987. Such organizations can apply for ADSSP grants and lay out plans for implementation, including training and licensing interventionists. Because the grants go through the state government, these organizations are given a certain amount of guarantee that local AAAs will cooperate with them. However, grants alone are not enough to sustain these NGOs. Institutions such as the RCI and

the Benjamin Rose Institute on Aging, which developed Care Consultation, rely heavily on private funding and donations.

Once an EBP is approved for ADSSP funding, the money goes into training staff to implement the programs with caregivers. Being part of the EBP package, such training is usually licensed and certified, meaning that only persons trained over a certain period of time by master trainers are qualified to run the programs. This step ensures fidelity and quality control, so that the programs produce the expected results of the EBPs. An indirect outcome of this process is that it creates a pool of caregiver support professionals, a new specialized profession in the human services. Our changing demographics, the increase in the proportion of the elderly to the total population, points to the prognosis that the demand for such a professional class will rise in the near future. Hence it is timely that the implementation of EBPs is creating such a pool.

The implementation process itself will be borne from a collaboration among the State government, local AAA, and whichever NGO that participates in this process. In searching and reaching out for prospective participants, AAA will be able to locate and identify family caregivers in their local communities. This process will make it easier to send out information on programs and assistance, and reach out to them when the need arises.

By participating in EBPs, family caregivers should be able to overcome the adversities they face due to the caregiving process, but also become part of a wider network of caregivers. Participation in EBPs presents caregivers an occasion to identify and think of themselves as caregivers with unique needs. Such identification, encouraged by the coaching process embedded in the EBP, enhances self-awareness in caregivers, which encourages caregiver empowerment and advocacy. The increase in number of such caregivers will contribute to the rise of caregiving awareness at the social level, which in turn can pressure the government to allocate and spend more public funds on caregiver support.

Although the reach of EBPs is limited due to the small scale of budgets and grant-based allocation, the adoption of such programs contribute to creating an infrastructure that can deliver high-quality support programs to caregivers by formally trained specialists, based on a collaboration of interested organizations (public and

private) that share the same goals and concerns on caregivers.

Conclusion

This study was conceived under the realization that despite Korea's long-term care insurance policy, the elderly were still being cared for by family members, who themselves are "hidden patients," due to the strains of caregiving (Kwon, 2012). We concur with previous researchers that have called for a formal policy that specifically supports family caregivers, such as the policies offered in the U.S. and Great Britain. With the aim of providing a concrete reference point for Korea, this study has sought to present how the U.S.'s family caregiver support policy is enacted and implemented at the state and local levels, and the specific programs and actions this policy comprises of. By focusing on the case of Georgia, we found that federal funds from the NFCSP and ADSSP were channeled to assist caregivers with respite care and consumer directed-care, while also providing them with (mostly) one-on-one caregiver support through EBPs, which were administered at relatively low costs while also contributing to building a functioning local caregiver support infrastructure. Based on our findings, we would like to make the following suggestions to complement Korea's long-term care policy.

Firstly, Korea has not yet reached a social consensus on who a caregiver is, what he/she does and whether caregivers are entitled to government support. An underlying problem beneath this absence of family caregiver support programs lies in the lack of awareness on caregiving in general. Despite drastic changes in lifestyles (working hours, women in the workforce, etc.) that make family caregiving difficult to sustain, cultural tendencies that see caregiving as an extension of filial piety persist. The emphasis on the moral aspect of caregiving, pressures caregivers into thinking that seeking help is selfish and inappropriate. Few family caregivers are vocal in sharing their experience, and consequently there are no organizations that speak on behalf of caregivers. The U.S. has the National Family Caregiver Alliance, and in Great Britain, Carers' UK has advocated for caregiver support. In the U.S., NGOs such as the Alzheimer's Association and AARP have actively campaigned to raise caregiver awareness and provide information and resources for caregivers. Think tanks

and university research centers, such as the RCI, have been active at the national and local level in research and development of programs, and in their translation and implementation. Korea has an Alzheimer's Association, but it is not as well-funded and as active as its American counterpart, and has few, if any, programs or information for family caregivers (Alzheimer's Association, Korea). There is also a Korean Association for Dementia, whose members are mostly from professionals working with Alzheimer's patients, but their website does not cite family caregiver support programs (a contrast to the American AA and AARP websites) (Korean Association for Dementia). Our first suggestion is that the creation of a publicly funded caregiver support program can form the basis for caregiver self-identification. Such a formal adoption would also validate the work of family caregivers and increase their visibility.

Secondly, the American experience tells us that building a caregiver support system cannot be undertaken by one entity alone, that it is a product of collaborative efforts by different parties that have their own history and expertise on the subject. Securing public funding for R&D can act as a catalyst to create an infrastructure for family caregiving support, and thus is indeed a necessary, but not always a sufficient condition. Taking cues from the AARP, pension funds and retiree associations that have a solid financial and organizational foundation, such as the Korea Teachers' Credit Union, are in a good position to raise family caregiver awareness and provide private funding. University research centers can contribute by running randomized control trials to develop programs tailored to Korean family caregivers. Our second suggestion is that diversifying funding sources and making use of a division of labor is crucial in building a working system.

Thirdly, we should take notice of how EBPs have evolved and improved over the past few years. "Support programs" in Korea are still understood to generally refer to group programs, and only the City of Seoul seems to be offering family caregiver support group programs. The Hope Diary, an on-site EBP group program, has been implemented in Seoul's 12 Centers for Dementia since 2011 (Seoul Metropolitan Center for Dementia, 2015). Caregivers can surely benefit from group programs, but recent EBPs are shifting towards individual one-on-one programs. Specifically,

the telephone and web-based interventions we have seen are cost-effective and positively impact caregivers. EBPs implemented in the U.S. can be a useful reference in the development of our own programs, which can reduce trial-and-error and save development and implementation costs in the long run.

In this study, we have also sought to demonstrate how the implementation of EBPs creates an infrastructure that works as a comprehensive caregiver support system at the state and local levels. Hitherto research on family caregiver support programs in the U.S. mostly focused on the national/federal level, by identifying the legal basis and policy objectives concerning family caregivers. Our study found that securing public funding by law can be a significant starting point, but that a virtuous cycle of successful caregiver support is accomplished when federal incentives work in conjunction with state and local initiatives.

Nevertheless, this study has the following limitations. First, due to restrictions in the availability of public documents, our research consists of an exploratory, descriptive study rather than an in-depth case-study. We have sought to complement facts gathered from government reports with data collected through on-site interviews with service providers. In future studies, in-depth case studies of different AAAs and their programs for family caregivers can shed light on how the NFCSP and ADSSP are implemented at the local level. Secondly, this study does not offer an exhaustive review of all the family caregiver support programs in the U.S. Due to regional differences, the programs chosen and implemented vary from state to state. We have confined our findings to the case of Georgia, which has a history of successful involvement regarding family caregiving. Thirdly, although this study introduces various EBPs for family caregivers, it does not purport to give a comprehensive evaluation on their quality and efficacy. This task, which entails referencing the point-of-view of the service user rather than the service provider, lies beyond the objective of this study and should be investigated in subsequent research.

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