

A Telephone Support Program for Adult Day Center Caregivers: Early Indications of Impact

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Abstract

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support Pilot Program was developed as a service-learning experience for graduate students to address the need for family caregiver support services. The Telephone Support Program was developed by the Virginia Commonwealth University Department of Gerontology, in collaboration with A Grace Place Adult Day Center, as a pilot project that introduced a low-tech telephone outreach initiative in which trained students provided weekly caregiver support through active listening. Uniting students with family caregivers provided a challenging learning experience for students that enriched students' personal and professional development, provided an important service for caregivers, and met a critical community need. The findings demonstrate that a telephone support format offers a positive educational experience for graduate students and essential psychosocial support for family caregivers.

Setting the Context

Virginia Commonwealth University is a large, urban, public, doctorate-granting research university with more than 32,000 students enrolled in 208 certificate and degree programs. Located in the heart of the capital city of Richmond, Virginia, on two downtown campuses, Virginia Commonwealth University has a long history of commitment to community partnerships and was one of the first universities in the nation to be recognized by the Carnegie Foundation as a community-engaged campus. The university's strategic vision, as outlined in *VCU Quest for Distinction (2011)*, is built on four core themes, one of which is to become a national model for community engagement and regional impact.

The Department of Gerontology at Virginia Commonwealth University offers a variety of graduate degree programs emphasizing interdisciplinary interaction and a biopsychosocial approach to the aging process. The Department of Gerontology focuses on the development of career and professional identity of students through community engagement, experiential learning

opportunities, and service-learning courses. Experiential and service-learning opportunities are developed through partnerships with community agencies and organizations that serve older adults and their family members. The Virginia Commonwealth University/A Grace Place Telephone Support Program is one such partnership that strives to meet a community-identified need while providing a hands-on service-learning experience for graduate students.

A Grace Place Adult Day Center is a Richmond-based 501(c)(3) nonprofit organization that provides essential health and social services to adults 18 years of age and older with significant disabilities or functional decline. The goal is to maintain the highest level of independence and quality of life for adults while providing respite and support to their caregivers. In conversations between staff members at A Grace Place and Gerontology faculty members at Virginia Commonwealth University, A Grace Place staff members identified a need to increase emotional support for caregivers, identify at-risk caregivers, and provide education and resources for family members. In response to this need, an evidence-based (*Chang, Nitta, Carter, & Markham, 2004*), caregiver-centered support program was designed to address the stress and burden faced by caregivers of older adults. The goals of the Virginia Commonwealth University/A Grace Place collaboration included reducing burden and stress and connecting caregivers to needed resources, while respecting caregivers' busy schedules and responsibilities. To meet these goals, a telephone outreach support system was collaboratively developed by A Grace Place staff and Virginia Commonwealth University faculty, whereby trained graduate students provided telephone-based support through active listening on a weekly basis. The program responded to caregiver needs by providing referrals to the staff at A Grace Place Adult Day Center, who provided targeted assistance that met the caregivers' needs.

This article details the development of the Virginia Commonwealth University/A Grace Place Telephone Support Program for Caregivers. The article begins with a review of the caregiver support literature, specifically highlighting telecommunication interventions, and then discusses the benefits of a caregiver/student support model as an important educational tool and learning experience for students. The development of the Telephone Support Program is then described, and the findings on student learning and benefits to the community and caregivers are reported.

Literature Review

Family caregivers of frail elders report significant stress as a result of the increased burdens and responsibilities they face on a daily basis. There is ample evidence in the literature that caregiver burden has a negative impact on both the caregiver, in terms of mental health and physical illness (*Kiecolt-Glaser & Glaser, 2001*), and the care recipient, who may subsequently be at greater risk for institutional placement (*Zarit, Bottigi, & Gaugler, 2007*). Recent research has suggested that programs such as respite, support groups, counseling, and educational sessions have little effect on decreasing the burden that many caregivers experience (*Winslow, 2003*). In addition, many caregivers are unable to utilize support services due to logistical complications, including arranging alternative help for their loved one, scheduling conflicts, work conflicts, physicians' appointments, and managing personal responsibilities (*Wright, Lund, Pett, & Caserta, 1987*).

An emerging literature has begun to explore how technology, such as the telephone and Internet, can be used to facilitate caregiver intervention (*Bank, Arguelles, Rubert, Esorfer, Czaja, 2006; Czaja & Rubert, 2002; Finkel, Czaja, Martinovich, Harris, & Pexxuto, 2007*). Unlike standard support groups, which require participation away from the caregiver's home, distance support programs allow the caregiver to remain at home while receiving support through telephone conversations, e-mail exchange, or other forms of electronic communication. Caregiver telephone support programs provide psychosocial support, information, and education to caregivers while taking into account the caregivers' limited time and resources. Finkel et al. (2007) conducted a pilot study examining the efficacy of a psychoeducational intervention via telephone utilizing health care professionals. Study results indicated a significant decrease in caregiver burden and depression. According to Colantonio, Cohen, and Corlett (1998), caregivers express a preference for telephone support over in-person group settings. In addition, Smith and Toseland (2006) found that telephone support decreased the amount of strain and depression for adult caregivers. Telecommunication strategies can effectively address the problems of non-use, irregular attendance, and attrition seen with caregivers in a standard support group format. Research on caregiver support models has examined implementation, long-term sustainability, and the impact on caregiver stress. However, little research has focused on the potential benefits of caregiver education for students.

Spier and Yurick (1998) conducted a caregiver support program aimed at influencing the learning outcomes of undergraduate nursing students. In this program, nursing students worked with community-based caregivers in order to develop sensitivity and improve skills in assessment and communication. Students preparing to work in the health or allied professions will, in all likelihood, work with informal family caregivers during the course of their careers. To address this need for increased knowledge about caregiving, Middle Tennessee State University developed a specific online caregiving course for social work students (Taylor, 2004). The Virginia Commonwealth University/A Grace Place collaborative builds on these two projects by developing an innovative high-touch, low-tech caregiver telephone support program that concurrently provides hands-on caregiver education for students as well as an essential psychosocial intervention for caregivers.

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support Program

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support Program aims to increase university graduate students' awareness of the challenges faced by home-based caregivers. The training component of the program requires graduate students to participate in a 6-hour training session that introduces caregiving concepts and develops skills in long-distance relationship building and active listening. The curriculum was developed by Virginia Commonwealth University Department of Gerontology faculty, who had expertise in the biopsychosocial aspects of aging and caregiver education, as a toolkit to address long-term sustainability and ease of replication. The training toolkit was developed as a compilation of best practice approaches to active listening and long distance relationship building (Chang et al., 2004; Mason & Harrison, 2009). The five training modules contained in the toolkit involve readings, didactic instruction, and group activities (Table 1). The curriculum was specifically designed to address individual differences in the caregiving experience; for example, Module 5 details cultural perspectives on caregiving. The training toolkit includes fact sheets on diverse ethnicities and provides reference sheets on culture and cultural norms related to caregiving. Understanding and respecting diversity was a cornerstone of the training and was integral to the overall effectiveness of the Caregiver Telephone Support Program.

Table 1. Overview of Training Toolkit

Module	Student Learning Outcomes	Description
1: Caregivers Sharing Their Stories	<ul style="list-style-type: none"> • Raise awareness of caregiver experiences • Introduce students to the mission of the community partner 	The training program began with two caregivers from A Grace Place sharing their experiences. Varied speaker experiences underscored the diversity of caregiver situations.
2: The Caregiver Experience	<ul style="list-style-type: none"> • Learn terminology for caregiver stress/burden/burnout • Students learn ways to promote caregiver health in body, mind, and spirit 	Caregivers must experience person-centered care as surely as care recipients. If “caregiver burden” becomes overwhelming, it may lead to “burnout,” making the caregiver unable to function.
3: Telephone Support Programs	<ul style="list-style-type: none"> • Learn the importance of the low-tech and high-touch approach for working with caregivers 	Overview of the literature on success of technological support programs. Overview of the evidence base and the value in providing social and emotional support to caregivers.
4: Relationship Building and Active Listening	<ul style="list-style-type: none"> • Learn active listening strategies • Learn culturally competent communication strategies 	Relationship building through phone interaction. Active listening strategies and roadblocks were presented and students participated in role play exercises to demonstrate these strategies.
5: Empathy and Support: Respecting Individual Differences	<ul style="list-style-type: none"> • Learn strategies to respect individual differences • Discuss potential topics for discussion with caregivers • Discuss how to identify caregiver needs 	This module emphasized the uniqueness of the caregiver experience. Emphasized active listening as an empathic response. Encouraging freedom to communicate experiences without fear of judgment.

Pilot Program

A 14-week Caregiver Telephone Support Program pilot took place from January to May 2010 with 32 caregivers, four graduate students from the Department of Gerontology, and four graduate students from the Department of Occupational Therapy. After all 32 caregivers were contacted, 21 elected to participate in the program. The caregivers ranged in age from early 40s to late 80s.

Twenty-five percent of the caregivers were caring for a parent, 25% were caring for a sibling, 25% were caring for other relatives, 15% were caring for a child, 5% were caring for a spouse, and 5% were unreported. Graduate students in the pilot project ranged in age from early 20s to late 50s and consisted of seven females and one male. Students received the 6-hour training prior to beginning the telephone support calls.

From Pilot Program to Graduate-Level Service-Learning Course

After the pilot project was completed in May 2010, the Caregiver Telephone Support Program format was used in the fall 2010 semester as a service-learning project for a graduate-level class titled *The Biology and Physiology of Aging*. During this 15-week service-learning course, 22 gerontology and certificate in aging studies graduate students, and 22 caregivers participated in the project. The curriculum was modified due to time constraints, and excluded the group activities. The participating students represented both master's in gerontology and certificate in aging studies students who live locally ($n = 8$) as well as students who took the course as an online, distance education class ($n = 14$).

Evaluation Methods

This study was approved by the Institutional Review Board of the participating university. Data collected during the pilot project focused primarily on measuring student learning. Student learning was evaluated using detailed case notes collected by the students after each phone call with a caregiver, as well as student journals. Student case notes were analyzed to generate categories and themes that reflected student learning throughout the course of the semester.

Caregiver outcomes and satisfaction with the Telephone Support Program were evaluated through interviews with the caregivers that were completed at the end of the pilot program. Interviews were conducted by a student via telephone with each caregiver participating in the pilot program. In addition, the students completed intake forms in order to track topics discussed and student perceptions of the emotions exhibited during the support calls. Intake forms were used to help students track caregiver needs and were shared with A Grace Place staff on a monthly basis. Finally, community partner outcomes were evaluated through interviews with A Grace Place staff conducted at the end of the pilot program by Virginia Commonwealth University faculty.

Student Learning Outcomes

Analysis of call notes and journals indicated a valuable learning experience for students that improved both relationship building and listening skills. The success of this program, in terms of student learning, was anchored by the students' perception of benefits provided to the caregivers through social support and triaging provided to A Grace Place staff. Many of the students had positive attitudes toward the program because they felt that they were providing valuable help to the caregivers.

Most valuable experiences.

The students were able to develop meaningful relationships with some of the caregivers and felt that they were able to offer help and emotional support through the weekly phone calls. Students learned about the daily struggles of caregiving and the emotional and physical strain that caregivers often endure. Students reflected on the caregivers' overwhelming responsibilities to the care recipient, to outside jobs, and to additional family members. These responsibilities created a lack of time and resources to seek needed services, and students developed an increased awareness of these caregiver stressors as a result of the program. As future gerontologists and gerontological specialists, students felt that they gained valuable knowledge that would benefit them both personally and professionally.

Being a part of this program, even if for a short time, will greatly impact my future practice . . . Family and caregivers can be overlooked, and their importance in the entire process was solidified for me in this program . . . In my future practice, I will take the time to collaborate and listen to the caregiver. I will also make sure that they are able to take respite time and take care of themselves . . . I have enjoyed talking to my caregivers. I learned that the caregiver is just as important as the loved one they are taking care of . . . I also learned that small gains can be huge to the caregiver . . . I also learned that listening can be hard at times.

There is one caregiver that I have talked to every other week consistently. I know that I have made a difference in this caregiver's life and that he deeply appreciates the opportunity to vent his concerns, frustrations, and triumphs to me. I have thoroughly enjoyed my phone calls

with this caregiver, and feel that he has really taught me the importance of being an advocate for those who cannot advocate for themselves.

Barriers and challenges.

Overall, the biggest barrier students experienced with the Caregiver Telephone Support program was trying to contact the caregiver over the phone in order to set up support calls. Students were unable to reach some caregivers as much as several weeks into the program. Sometimes, when the student was able to reach the caregiver, the caregiver was unaware of the nature of the program, and in several cases did not recall signing up to receive these services. Additionally, in a few instances student and caregiver personalities did not match.

The caregiver was very negative, almost rude, as if I should have known that it is not appropriate to call her after 8:00. Staff support indicated that this caregiver is extremely stressed right now and may consider talking to me a burdensome responsibility.

I learned that although the caregivers signed up to receive telephone support service, most of them have little to no knowledge about the program. Many of them show reservations about the contact.

These findings emphasize the importance of clear and consistent processes for communication between the university and the community agency and between the community agency and the caregiver throughout the program.

Caregiver outcomes.

Overall, the caregivers reported positive experiences engaging with students. In most cases, the caregivers reported that they enjoyed having someone to talk to, not only about their caregiving difficulties, but about their lives in general. Many of the caregivers felt that these calls provided therapeutic value, allowing them to digress from their daily obligations. Others felt that they were helping the students learn more about what it means to be a caregiver. Caregivers indicated that it was helpful to verbalize

their frustrations and concerns to someone removed from their personal situation.

It was good to be able to articulate the difficulties of caregiving. The student showed interest in what I wanted to say. Sometimes it seemed helpful to just talk about the situation and the challenges.

It was an emotional time for me because my mother had just gone into a nursing home. I cried all the time. My student did not judge me. I had a lot of guilt, and talking helped.

I am stressed because I have a job, and I take care of my 88-year-old mother. It gave me a break and helped my stress. I remember the first call I had was when I was having a bad day. It really helped.

I really enjoy the phone calls that I have been receiving from the support service and I told my co-workers how nice it has been to have someone to talk to.

Student intake notes reported that frustration, guilt, and sadness were the most frequent emotions displayed by the caregivers during the course of the phone conversations (Table 2). Intake notes also demonstrated that health issues, resources, and time for self were the most frequently talked-about topics during the course of the phone conversations (Table 3).

Table 2. Emotions Exhibited by Caregivers During Support: All Calls

Emotion	%
Frustration	33
Guilt	15
Sadness	10
Resentment	9
Hopelessness	5

Table 3. Topics Discussed by Caregivers During Support: All Calls

Topic	%
Health Issues	56
Resources	54
Time for Self	54
Family Support	32
Financial Responsibilities	32
Children Responsibilities	29
Job Constraints	28
Sleep Problems	10

Community partner outcomes.

End-of-semester interviews with A Grace Place staff were conducted by the first author. One staff member reported increased knowledge about their clients' caregivers, including both personal characteristics and specific needs. Other staff members indicated that through the information gained from the student and caregiver conversations, they were able to assist some of the caregivers with the resolution of specific identified stressors. Feedback from A Grace Place staff included:

It can be difficult to maintain an objective balance, especially when things get hectic, input from the caregivers and students during this program have [sic] been good for my perspective.

I know that I have learned a great deal about both the clients and caregivers through their dialog with the volunteers. This has been so helpful, since I just don't have the time available to give everyone the attention that I would like to give them.

Lessons Learned

Several important lessons were learned during the development and implementation of this program. First, student training was critical to the success of the program. Exposure to best practice, evidence-based information on relationship building, and empathic listening enabled students to provide appropriate discussions and outreach to caregivers. Second, communication between faculty members, students, and staff members from A Grace Place

was also a critical element of the program. A systematic approach for providing updates on caregiver issues and concerns that arise during support calls proved to be a critical best practice. As in previous research, the telecommunication outreach strategy in this program was well-received by caregivers, and did not pose a barrier to the development of good rapport between students and caregivers.

Program Challenges

Implementation of the Telephone Support Program posed several challenges. Students in both the pilot project and service-learning class were discouraged from providing caregivers with their personal phone numbers. This policy was established in order to protect the students from unstructured or impromptu phone conversations, but also resulted in a slower start to the student-caregiver dialogue in instances when the caregiver missed the student's first few telephone call attempts. In the future, this phone connection issue can be resolved through programs such as Google voice accounts, which provide options for using secure phone numbers rather than personal phone numbers. Another challenge was the additional burden placed on A Grace Place staff to manage caregiver problems reported to them by students, problems that would have otherwise gone unreported.

Implications and Future Directions

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support Program involved a collaborative relationship between the Virginia Commonwealth University Department of Gerontology and A Grace Place Adult Care Center. The primary benefit of participation in the program for A Grace Place Adult Care Center was increased volunteer staffing resources to meet critical needs in the community. For the Department of Gerontology, the Caregiver Telephone Support Program offered an important educational and experiential learning opportunity for students and facilitated the development of stronger relationships between the university and community-based service providers while upholding the department's mission to "Improve Eldercare through Education" and ultimately improve lives of older adults and their caregivers.

The Caregiver Telephone Support Program was designed to provide an educational experience for students while concurrently addressing an important need for family caregivers. As a

service-learning class, the Caregiver Telephone Support Program holds great promise for both graduate and undergraduate students across a wide variety of disciplines from psychology and sociology to geography and communications. The model can also be utilized as a service-learning project within distance education classes. Beyond providing active listening support to caregivers of aging or sick family members, service-learning students could provide telephone support to other community members, such as new teen parents or at-risk youth.

Low-tech technology, such as telephone support, can also be combined with newer technology, such as smartphones, blogging, texting, and tweeting for both caregivers and university students. In the pilot project, students could blog about their experiences in the program and share information with each other through a private social website. In The Biology and Physiology of Aging service-learning class, students were able to meet weekly to discuss their experiences with the caregivers, so blogging was not necessary. Future directions for university students can include the use of smartphone technology to complete the orientation training, and texting or e-mailing to communicate with caregivers. Technologies, both high- and low-tech, appear to hold great promise for improving home-based caregiving.

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support program will continue to be utilized as a service-learning experience for graduate students. Program impact will be evaluated longitudinally using a mixed-methods design. Through this study, the relationship between students' professional identity development and their experience in the Telephone Support Program will be explored, as will the effect of program participation on caregiver mental health.

The Virginia Commonwealth University/A Grace Place Caregiver Telephone Support program was specifically designed as a high-touch and low-tech program in order to make the program both effective and accessible to all family caregivers and students. This and similar programs promise to provide a 21st century, technologically friendly learning experience for students while still providing caregivers with the high-touch, hands-on care that they require.

References

- Bank, A. L., Arguelles, S., Rubert, M., Esdorfer, C., & Czaja, S. J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *The Gerontologist*, 46, 134–138.

- Chang, B. L., Nitta, S., Carter, P. A., & Markham, Y. K. (2004). Perceived helpfulness of telephone calls—providing support for caregivers of family members with dementia. *The Journal of Gerontological Nursing, 30*(9), 14–21.
- Colantonio, A., Cohen, C., & Corlett, S. (1998). Support needs of elderly caregivers of persons with dementia. *Canadian Journal of Aging, 17*, 330–345.
- Czaja, S. J., & Rubert, M. P. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine Journal, 64*, 469–476.
- Finkel, S., Czaja, S., Martinovich, Z., Harris, C., & Pezzuto, D. (2007). E-Care: A telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psychiatry, 15*(5), 443–448.
- Kiecolt-Glaser, J. K., & Glaser, R. (2001). Stress and immunity: Age enhances the risks. *Current Directions in Psychological Science, 10*, 18–21.
- Mason, B. J., & Harrison, B. E. (2009). Telephone interventions for family caregivers of patients with dementia. *Alzheimer's Care Today, 10*(3), 172–178.
- Smith, T. L., & Toseland, R. W. (2006). The effectiveness of a telephone support program for caregivers of frail older adults. *The Gerontologist, 46*(5), 620–629.
- Spier, B. E., & Yurick, A. (1998). Alzheimer's disease caregiver support: Impact on student learning. *Geriatric Nursing, 19*, 142–145.
- Taylor, J. E. (2004). Teaching university students family caregiving online. *Educational Gerontology, 30*(5), 423–431.
- Virginia Commonwealth University, Quest for Distinction (2011). *Report of the VCU Strategic Plan: Quest for Distinction: Success. Discovery*. Impact. Retrieved from <http://www.future.vcu.edu/plan/index.html>
- Winslow, B. W. (2003). Family caregivers' experiences with community services: A qualitative analysis. *Public Health Nursing, 20*(5), 341–348.
- Wright, S. D., Lund, D. A., Pett, M. A., & Caserta, M. S. (1987). The assessment of support group experiences by caregivers of dementia patients. *Clinical Gerontologist, 6*, 35–59.
- Zarit, S. H., Bottigi, K., & Gaugler, J. E. (2007). Stress and caregivers. In G. Fink & Associates (Eds.), *Encyclopedia of stress* (2nd ed., pp. 416–419). San Diego, CA: Academic Press.

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