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Male Caregivers: Breaking through the Male Self-Sufficiency Barrier to Help Those in Need

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Case Study

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James J. Hutchinson

Educational Objectives

1. To generate awareness of characteristics and issues specific to male caregivers;

2. To examine successful strategies for education and awareness programs that motivate male caregivers to request services when needed;

3. To identify effective services targeted to male caregivers that have been initiated by three Area Agencies on Aging that received funding from the Virginia Department for the Aging.

Background

The increasing number of male caregivers has presented Area Agencies on Aging and other service providers with a challenge. Most existing caregiver data has been based on the experiences and needs of the female caregiver, for men have been reluctant to seek assistance. Increasingly, however, men are becoming caregivers. Dementia, particularly Alzheimer's disease, appears to strike women in higher numbers than men, and male caregivers are assuming care of their loved ones.

Realizing this, the Virginia Department for the Aging (VDA) applied for and was awarded a three-year grant (2001-05, with extension) by the US Administration on Aging to develop male caregiver outreach programs. VDA selected three Area Agencies on Aging (AAA), with differing male caregiver demographics, to participate in the grant to develop a broad study of male caregivers. Each AAA designated a project coordinator or ombudsman who sought out male caregivers, addressed their specific needs as male caregivers, and connected them with relevant programs and services. The three AAAs that participated in the project were: Crater District Area Agency on Aging, Petersburg, which focused on male caregivers in rural areas; and Peninsula Agency on Aging, Newport News, and Senior Services of Southeastern Virginia (SSSEVA), Norfolk, both of which focused on male caregivers who are retired military. This case study will focus on SSSEVA but will report, as well, the overall results from all three AAAs.

MMAC

The Male Military Advocate for Caregivers (MMAC) program of SSSEVA sought to identify,
educate, and provide services to the retired male military caregiver. Historically, these men, like older rural men, tend not to seek support from other family members, friends, or others if they are faced with a challenging caregiving situation. They are less likely to participate in caregiver support groups or to seek information and assistance from these types of peer group activities. This project provided outreach to male caregivers and provided a support system that helped them continue in their caregiving role.

Project Outreach

Creating program awareness presented a challenge due to a lack of research on how to locate male caregivers. This generated the question, "Where do men congregate?" The two AAAs focusing on military retirees were able to start with organizations that drew these individuals as their primary members (such as the VFW and the various service retiree clubs). Each of the three AAAs in the project reviewed their resources and, through trial and error, discovered the places that were most successful. Two resource patterns emerged, universal and regional. Universal resources are those common to all three AAA districts participating in the grant. They include, but are not limited to, the following: faith based organizations; predominately male organizations (Moose, Lions Club); support groups (Alzheimer's Association, American Cancer Society); and senior clubs and centers. Regional resources are those unique to a location and population, such as military facilities (base clinics, hospitals); local businesses (barber shops, restaurants); sports venues (bowling alleys, golf courses); and local partnership programs (Pharmacy Connection Program, Making the Link). Once the projects established the most appropriate locations, the program coordinators developed working relationships with influential individuals at each, and were thereby able to give presentations, distribute newsletters, and offer male caregiver workshops, all of which helped identify male caregivers.

Education and Awareness Programs

After identifying the male caregiver in need of assistance, the next obstacle was to convince him to accept support. The direct approach may not always work. Providing awareness and education was found to break down attitudinal barriers. The three most effective methods of awareness and education were: male caregiver workshops, cooking classes, and support groups; newsletters and flyers specifically targeted to male caregivers; and health fairs and resource expos.

Services

Providing services to the male caregiver is the one goal all three AAAs participating in the grant program say was a total success. They identified respite care as the one service most needed by male caregivers. In addition, the three projects offered homemaker services, transportation, and home-delivered meals.

Case Study #1

Mr. C is a 65-year old U.S. Navy retiree, with colon cancer, and the sole caregiver for his spouse. His wife has Alzheimer's disease with hallucinations and neuropathy that makes her prone to falling. As a military retiree, Mr. C and his spouse obtain most of their health care from the military medical centers, which is typical for military retirees who live near a base.

In March 2003, Mr. C was informed that he had colon cancer and needed an operation requiring a short recovery period. Realizing he would need assistance with his wife's care, Mr. C, like many military retirees, turned to the military hospital social worker seeking assistance for his wife during his hospital stay and recovery time. Because the Male Caregiver Program had provided information to the military hospital social work staff, Mr. C was able to access this new community resource.
In his own words, Mr. C said, "I telephoned the Portsmouth Naval Hospital social worker who told me to contact Senior Services of Southeastern Virginia. I called and set up an appointment for the following day with Mr. Hutchinson, their Male Military Advocate for Caregivers. Mr. Hutchinson and Bonnie Ellick, one of their Care Coordinators, helped set up seven days of in-home respite care for my wife while I was in the hospital. They also arranged three days of care for me when I returned home after surgery. I can't imagine what I would have done without this help."

In addition to the initial respite care, a handicap ramp was built for his wife's motorized chair in June 2004 (provided through the agency's Senior Skills Program), and in March 2005, Mr. C received another seven days of respite care.

In this case, MMAC had identified Portsmouth Naval Hospital as a primary resource for locating retired male military caregivers and had established a working relationship. This resulted in Mr. C's referral to the Male Caregiver program at SSSEVA. Having a program for male caregivers with a retired military man as the program coordinator in a heavily retired military community made it easier for him to open up to help and to accept services. Once the male self-sufficiency barrier is broken, he and other male caregivers accepted additional services, realizing that help is available and there is no stigma attached to asking for help.

**Case Study #2**

Mr. H was an 82-year old Navy retiree with ESRD (End Stage Renal Disease) requiring dialysis three days a week. Mr. H's ESRD precipitated a number of additional illnesses, including episodes of fainting which resulted in his not being able to get to his feet until he called someone for help or a neighbor came by to check on him. Mr. H was the sole caregiver for his 86-year old spouse who had Alzheimer's disease and required a variety of help with her activities of daily living (ADLs), including feeding, toileting, bathing, and medication supervision. Mr. H's neighbor, also a retired Navy man, called the Navy Family Service Center (NFSC) seeking help for his friend and neighbor. The NFSC recommended he have his neighbor call SSSEVA for assistance through the Male Caregiver Program.

According to Mr. H's daughter, Mr. H and his spouse had made a pact to live in their home until they died. Each had stated they did not want to be placed in a long-term care facility. Although he had the services of a paid caregiver who stayed with his spouse while he was at dialysis, this did not help the situation when he fell. When Mr. H fell, he would do one of three things: call his neighbor, wait until the paid caregiver arrived, or just wait until he had enough strength to get up on his own. He knew if he called 911, his situation would be referred to Adult Protective Services and he feared they would move his spouse into a long-term care facility. As a result of his falls, Mr. H's spouse would be without care for hours or even days, causing her condition to deteriorate further.

Repeated attempts were made to assist Mr. H and his spouse, but they always refused services. In August 2004, Mr. H went to his regular dialysis treatment and was found to be so ill that he was transferred to the hospital. He died within two weeks. The Male Caregiver Program was able to assist his daughter in locating a long-term care facility for the spouse, who died several months later.

Unlike Case Study #1, where the Male Caregiver Program was able to use outreach and intervention tools to achieve a successful resolution, our work with Mr. H was largely unsuccessful. Although Mr. H had initially sought help from a part-time paid caregiver, the self-sufficiency barrier coupled with the fear of institutionalization limited his willingness to accept additional help from
the Male Caregiver Program. The major barrier to helping was the pact they had made to live in their home until they died, reinforced by their fear of moving to a long-term care facility. This case is a classic example of how a special program with all the key elements in place may not always guarantee success.

**Evaluation of All Three Projects**

The Center for Excellence in Aging & Geriatric Health (CEAGH) at The College of William and Mary developed and conducted an evaluation of the overall grant program, including the projects of all three AAAs. Some of the findings follow: 189 male caregivers (unduplicated count) participated in the program; the projects contacted 413 local community organizations about family caregiving and gave 319 public information/education group presentations to 17,776 people to increase public awareness of the project and solicit male caregivers for the project; distributed 13,032 home-delivered meals to 139 male caregivers and/or their care recipients; and published 11 bimonthly editions or quarterly editions of male caregiver newsletters.

Selected other findings included: 1) Male caregivers reported a need for information about available resources and services. Providing information and resources is a critical means by which to reduce male caregiver stress while enhancing their ability to maintain their caregiving role; 2) Connecting male caregivers with local services, including home-delivered meals, transportation, homemaker services, and respite care has helped make it possible for care recipients to remain in the home for a longer period of time; 3) Men do not identify with the role “caregiver” the way women have. Other terms such as care partner may be more suitable; 4) Men may experience embarrassment or guilt when needing to ask for assistance, yet they also report lacking information about available and accessible resources; and 5) Workshops offered by the project sites were well-received because they were viewed as educational in nature. It appears that inviting men to attend a support group is met with resistance because they see it as "only for women" or not structured enough to appeal to male participation. However, offering support groups targeted to male caregivers can prove beneficial; recognizing these groups as "networks" rather than "support groups" may lead to better reception by male participants.

**Conclusion**

The Male Caregivers Project clearly identified the need to alert men who are caregivers to the existence of relevant and available community services. Educating them about available services and how to access them is critical to reducing men's perceptions that services are only for the poor or for women. As well, it may be time to consider adopting additional or alternate terms to identify male caregivers, such as care partner or care companion. Overall, the outreach efforts of the three participating AAAs addressed a previously untargeted need, contacted hundreds of male caregivers, and offered services to assist them in their caregiving role.

**Study Questions**

1. How might you best use locations in your area where male caregivers might congregate, for outreach, awareness, and education?

2. What are some of the special needs of male caregivers and how do these differ from those of female caregivers?

3. How can you best serve the male caregiver? Remember, all your efforts are in vain if you cannot provide the services that are needed.

4. What approaches would you use to overcome the emotional barriers exhibited in the case of Mr. H?
References


About the Author

James J. Hutchinson (Jim), Navy Counselor Chief Petty Officer, USN, Retired, joined Senior Services of Southeastern Virginia (SSSEVA) in March 2003 as the Male Military Advocate for Caregivers (MMAC) Program Coordinator. His more than 20-year career in the military contributed to the success of the Male Caregivers Grant. Jim is currently SSSEVA's Virginia Insurance Counseling Program Coordinator.