



THE HSC HEALTH CARE SYSTEM
The HSC Foundation

Male Caregiving: Creating a Research, Programmatic, and Policy Agenda for an Emerging Public Health Issue

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OVERVIEW — *Currently, there is a dearth of research about male caregivers, including the ways in which they are similar to and different from their female peers. Little is known about men's caregiving experiences, physical and mental health status, or their interaction with professional health care providers. Studies of male caregivers from families and communities of color are almost nonexistent. Moreover, the literature on male caregivers focuses primarily on caregiver burden, failing to identify effective coping strategies and evidence-based interventions for improving caregiver quality of life. To address the present knowledge gap, The HSC Foundation, in partnership with the University of Maryland, College Park, and with additional support from the Consumer Health Foundation, convened a conference on this important but often overlooked issue.*

Male Caregiving:
Conference Briefing
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Male Caregiving: Creating a Research, Programmatic, and Policy Agenda for an Emerging Public Health Issue

As part of its Family Supports Initiative, The HSC Foundation, with the University of Maryland, College Park (UMCP), convened a conference on an important but often overlooked issue: men who play a primary role in caring for a loved one or friend. Held on May 2008, this conference focused on identifying the challenges and opportunities in creating evidence-based programs and policies to support the growing number of men in this role, including those caring for developmentally disabled or mentally ill children (both young and adult children), spouses, parents, other family members, and friends with physical limitations and/or mental illness. This report summarizes proceedings of the conference.

Background

Caregiving plays a key role in the long-term supportive services system in our nation and is an emerging public health concern. A 2004 study by the National Alliance for Caregiving and the American Association for Retired Persons (AARP) estimates that 21% of American adults (44.4 million) provide unpaid care for family members and friends above the age of 17; thousands more care for children with disabilities and chronic illnesses who will need lifelong assistance. Although the majority of these caregivers are female, recent studies indicate that approximately 40% are male. This group includes a wide variety of caregivers, such as fathers caring for children with special needs, husbands caring for wives with breast cancer, men assisting partners living with HIV/AIDS, and sons attending to frail, elderly parents. Notably, 60% of male caregivers work full-time.

Conference Proceedings

Framework for Male Caregiving

Dr. Suzanne Randolph, Associate Professor of Family Science at UMCP, reviewed an existing systemic model published by Ronda Talley and John Crews in the American Journal of Public Health (2007). Dr. Randolph discussed how this framework can serve as a useful starting point for addressing male caregiving as a public health issue and offered an expansion of that model designed to more fully address the needs of male caregivers.

According to this framework, public health professionals are seeking to improve the quality of life and support systems for diverse groups of caregivers, whose experiences involve multiple relationship and health dynamics. Caregiving is best viewed through a systemic, bidirectional model that consists of three main individuals: the professional caregiver, the family caregiver, and the care recipient, who may be of any age and experiencing a variety of physical and/or mental illnesses that create a need for care. These three individuals operate within an environment characterized by the following factors: more consumer choice, aging demographics, scientific discoveries, increased advocacy, a growing global disease burden, political forces, media portrayals about health and caregiving, growth in large health care systems, the insurance industry, increasing Internet access, and other issues in society at large. Each of these factors has an influence on caregiving and the development and dissemination of public health interventions designed to improve the well-being of caregivers and care recipients. Dr. Randolph also believes this existing systemic framework needs to be expanded to consider additional individual and environmental factors, including: culture, race, and ethnicity, and their related contextual factors (e.g., discrimination, racism, health disparities); other caregivers and caregiver support; workplace practices; education and training; research; legislation; and public policy.

Fathers of Children with Special Needs

Dr. Jan Greenberg, Professor of Social Work and Research Investigator at the Waisman Center of the University of Wisconsin-Madison, discussed current research about fathers who act as caregivers to children with special needs, including those with developmental disabilities or mental illnesses. He noted that most existing research focuses on mothers, with fathers viewed as distant figures in caregiving. Little is known about fathers as caregivers, especially gay men, men from communities of color, and low-income men. The term “caregiving” is a label imposed from the outside; most fathers who care for special needs children do not refer to themselves as “caregivers,” – they think of themselves simply as “father” or “dad,” and view caring for their children as being a normal part of that role.

Dr. Greenberg noted several similarities and differences in the experiences of fathers of children with developmental disabilities versus mental illnesses. Similarities include feelings of grief and loss, acceptance of limitations in their child’s ability to function independently, a tremendous need to provide caregiving and support to the child, and substantial fears about the child’s future. However, there are differences in the experiences as well, including that developmental disabilities are typically diagnosed at birth or shortly thereafter, while mental illness typically manifests in adolescence or young adulthood. Adult children with mental illness exhibit less stability than those with developmental disabilities, and due to social stigma, professionals and society tend to be more sympathetic to children with developmental disabilities than to those with mental illness. Because of these similarities and differences, there is a need to compare the experiences of both populations, so that both common and unique challenges can be identified and overcome.

Dr. Greenberg reported on key findings from developmental disabilities research on fathers of young children and on the few studies of older fathers of adults with developmental disabilities or mental illness. Mothers face a slightly greater caregiver burden than do fathers, although stress levels and depressive symptoms among both mothers and fathers are roughly the

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same. Fathers of children with developmental disabilities face unique challenges, including: role ambiguity; work and family life strain; challenges in interacting with health care professionals; worry about the child’s future; and the need to support their wives/partners. Fathers often have more difficulty coping with a son with a disability than a daughter because of perceived loss of opportunities to play the traditional role of mentor to a son. Fathers frequently look for support from their nuclear family and other close relatives, seeking family cohesion and successful adjustment to the situation. Some fathers use escape, avoidance, and mental disengagement to cope. Caring for an adult child with special needs can take a toll on fathers. However, fathers of children with special needs often report positive aspects of their experience.

Dr. Greenberg emphasized the need for further research, including comparative studies across different disabilities and studies involving diverse groups of fathers. He also called for the development of psychoeducational programs to meet the unique needs of fathers, including programs to support marital relationships and education and training of health service providers about the importance of father involvement. From a policy perspective, Dr. Greenberg called on employers and others to adopt policies to reduce levels of work-family strain, including more flexible work hours.

A Caregiver’s View: Father of Children with Special Needs

Mr. Oliver Roy is the father of children with special needs and a founding member of the Male Caregivers Advocacy Support Group of Health Services for Children with Special Needs, Inc. in Washington, DC. Mr. Roy noted that there are many services available to support fathers and spouses who have a child with special needs. However, many fathers will not ask for help, in part, because they do not define themselves as a caregiver until some critical event changes their life situation. Often fathers fail to take care of themselves, and there is a great need to make them aware of available support.

Male Caregivers of Spouses, Partners, and the Elderly

Dr. Edward Thompson, Jr., Professor of Sociology and Director of Gerontology Studies at Holy Cross College, discussed male caregivers of spouses, partners, and the elderly. He emphasized that men provide 40% of the nation's unpaid care work, and more men (58%) than women are involved in long-distance caregiving. Like their female counterparts, most male caregivers experience some disruption in their lives, particularly with respect to work, social activities, and financial well-being. Studies also reveal that male caregivers do not verbalize their feelings as willingly as women, and may fail to disclose their burdens to friends, coworkers, physicians, and others. Some male caregivers are embarrassed about helping their wives/partners with personal hygiene and daily activities. Several studies reveal that husband caregivers often worry about not being there for their wives, and feel more powerless, angry, irritable, and likely to use alcohol for self-medication than female caregivers. African American male and female caregivers report a higher level of spiritual well-being and a lower level of caregiver burden than do Whites.

Other research suggests that men adapt to caregiving with less adverse impacts on physical and mental health than women. For example, some studies indicate that male caregivers experience less caregiver burden, less anxiety, less role engulfment, and a greater ability to take respite time than do women caregivers. However, research also points to male caregivers' reluctance to use community services that might benefit them. Such failure to tap into community resources has been attributed to a number of factors, including men's fear of appearing they cannot handle the situation, unfamiliarity with available services/programs and their benefits, lack of other men using support services, and lack of identification with other caregivers.

A Caregiver's View: A Chinese Male Caring for His Mother

Mr. M. K. Lee, Director of Community Service for the Chinese Culture and Community Service Center in Gaithersburg, MD, shared his story of caring for his mother who had Alzheimer's disease. As a Chinese man, he had been taught to respect and care for his elders; sending his mother to an institution would have made him feel like an outcast in his cultural community. Because of his reluctance to share his experiences,

“More men than women are involved in long-distance caregiving.”

he remained unaware of the various support services that were available to him. Eventually he was forced to place his mother in an Alzheimer's facility. Looking back, Mr. Lee believes that his struggles could have been reduced if he had been more open with others and willing to seek social and community support.

A Caregiver's View: A Spousal Caregiver

Mr. Richard Anderson, currently a caregiver for his wife, notes that spousal caregivers are practically invisible. Mr. Anderson is the founder and President of the Well Spouse Association, an organization that provides peer-to-peer support, respite weekends, and an annual conference for 1,300 members, one quarter of whom are men. Mr. Anderson was a caregiver for his first wife for 29 years; after she died and he remarried, his second wife had a minor stroke, putting him in this role again. Lessons learned from his first experience include expecting that he will lose friends, understanding the need to seek help earlier, and knowing that he must be flexible and resilient. He hopes that social support will help him to reduce the stress and avoid the physical health problems linked to his first caregiving experience. Mr. Anderson urged spousal caregivers to obtain education and request assistance. The Well Spouse Association has two mottos: “you are not alone,” and “when one is sick, two need help.”

Evidence-Based Interventions for Male Caregivers: Challenges and Future Directions

Dr. Laura Gitlin, Professor of Occupational Therapy and Director of the Center for Applied Research on Aging and Health at the Thomas Jefferson University, reviewed evidence regarding the effectiveness of interventions designed to support male caregivers. She emphasized that the dominant theoretical framework for caregiver intervention research is the “stress-health process model” which focuses on potential stress and interventions to reduce emotional and behavioral responses to stress. This model does not address the potential for positive outcomes to emerge from the caregiving experience.

Dr. Gitlin noted that existing intervention studies focus primarily on women and have very small sample sizes of men or minorities. Outcome measures tend to be gender-biased and may not capture the benefits that men derive from intervention. However, the

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existing research, including results of the REACH (Resources for Enhancing Alzheimer's Caregiver Health) meta-analysis study and other studies of male caregivers have found that:

- Men who are caregivers provide roughly the same level of assistance as do women.
- Both men and women report high levels of behavioral problems among care recipients, and the objective burden facing both men and women caregivers is roughly equal.
- Women tend to be more upset and anxious and to have higher levels of depression than do male caregivers (although anxiety levels among men are also high).
- Men are more likely than women to report some positive aspects of caregiving.
- Women use social support more than do male caregivers.
- Females benefit more than males from current interventions in the areas being measured.
- Men have benefited most from an intervention designed to build hands-on skills (e.g., giving simple commands, laying out clothing, proper body mechanics for lifting).
- Men can learn concrete caregiving skills through psychoeducational and support group interventions, including basic education and video intervention/workbooks.

Dr. Gitlin stressed the need to test interventions that are specific to male caregivers, using well-designed randomized controlled trials and theoretical frameworks of stress that are meaningful to men. In addition, she encouraged developing and testing interventions for diverse male caregivers, including men from targeted cultural/racial groups; men with different relationships with the care recipient; men caring for individuals with various medical conditions; and men at different points along the care trajectory (e.g., from entry into the caregiver role to bereavement after the care recipient's death).

Best Practices for Male Caregivers: Views from Professional Providers

A panel of professional providers shared best practices for supporting male caregivers.

James C. Bridgers, Jr., Ph.D., a volunteer with the Male Caregivers Advocacy Support Group of Health Services for Children with Special Needs, Inc. in Washington, DC, discussed the role of support groups in assisting male caregivers. This

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group's three-hour weekly support meetings have not only educated men and provided moral support, but have also resulted in new caregiving services, such as a 24-hour hotline, referrals to other community-based support services, and a bus to transport the male caregivers and their children to the support group meetings.

Elmer T. Carreno, MD, Deputy Health Officer of the Prince George's County (MD) Health Department and an advocate working with the Latino population in Langley Park, Maryland, discussed the need to reach out to male caregivers. He stated that men are often unaware of existing programs and their benefits. Dr. Carreno called for more employer support and respite services. A new type of male-centric marketing message is needed, encouraging men to "ask for help" and to "take care of yourself." Information should be widely disseminated "where the men are" – in hospitals, long-term care facilities, churches, rotary clubs, golf clubhouses, and barbershops.

Dr. Kimberly Acquaviva, Assistant Research Professor at the School of Medicine and Health Sciences at George Washington University and Co-chair of the Lesbian and Gay Aging Issues Network, discussed how to support gay, bisexual, and transsexual male caregivers. One way to serve these caregivers is to be welcoming to them, clearly displaying a non-discrimination statement that mentions these populations (e.g., same-gender couples) and including images relevant to this group in marketing materials. Health provider training should reflect a commitment to serve this population by teaching staff how to be sensitive to their needs (e.g., including a partner option on the intake questionnaire).

Rev. Dr. James Lyons, Chaplain at the Erickson Retirement Communities, Inc., and Pastor of the Adelphi Bible Church in Adelphi, Maryland, discussed the importance of being a "Good Samaritan" when it comes to caregiving. Good Samaritans do not try to solve problems, but focus on listening and providing soothing, comforting care that is conducive to healing. Like all caregivers, Good Samaritans need outside help, including education and support groups, and they should not hesitate to access these services.

Creating a Research, Programmatic, and Policy Agenda for Male Caregiving

The final session, moderated by Dr. Randolph, focused on identifying programmatic, policy, and research recommendations for moving forward. Following is a summary of these recommendations, including ideas generated by attendees during small group discussions and other ideas developed by Drs. Koblinsky and Randolph based on the research papers commissioned for this conference. Recommendations are intended to help stakeholders:

- Increase population-based knowledge of caregivers, including the most vulnerable caregiver groups.
- Identify and address the health problems and hazards associated with caregiving.
- Translate knowledge of caregiving into practice and policy.
- Design and implement targeted, evidence-based interventions to support caregivers.
- Mobilize community partnerships to solve caregiving problems.
- Reduce inequities in health care systems, including supporting often-overlooked groups of caregivers and care recipients.

Programmatic Recommendations

- Develop evidence-based interventions specifically for men that address: the medical/mental health conditions of care recipients; different relationships between caregivers and care recipients (sons/daughters, siblings, spouses, partners, friends, parents, and members of faith communities); all stages in the caregiving process including bereavement; and the health status and needs of caregivers.
- Develop psychoeducational programs to meet the needs of fathers of children with different disabilities, including programs that address planning for a child's future.
- Design programs that support the marital/partner relationship of some male caregivers (e.g., caregivers of children or the elderly).
- Link male caregivers to community health and supportive services.
- Provide care managers to help men navigate the health care system since many male caregivers do not know who to call or where to go to access needed services.

- Educate service providers about the importance of male involvement in caregiving.
- When marketing services, use language that makes it clear that both male and female caregivers are welcome (e.g., use the term "family" rather than "maternal" to describe a program aimed at parents).
- Listen and probe for men's emotional responses to the caregiving experience.
- Creatively market male caregiving programs, focusing on places where men congregate.
- Create local, state, and national awareness of the issue of male caregiving, emphasizing that being a male caregiver is a normal experience.
- Inform health care service providers of the unique needs of employed male caregivers, including the importance of scheduling meetings and support groups when men can attend (e.g., after work hours).
- Develop programs to support "displaced" caregivers—caregivers who are left to live after the care recipient dies or gets better. Often these individuals have lost their jobs and may have no income or permanent housing because they were living with the care recipient.

Policy Recommendations

- Develop federal and state policies that alleviate the immediate and long-term burdens of caregiving (e.g., tax relief, income support, support for respite care, care locator services).
- Create policies that address the needs of the most vulnerable groups of caregivers.
- Develop policies that coordinate community services for caregivers and care recipients, and support multi-disciplinary teams from health, human services, faith-based, and consumer groups to tackle complex needs.
- Encourage employers to develop policies that reduce work-family strain for caregivers and that provide accommodations for male caregivers, such as flexible work hours and leave policies or access to adult day care facilities.
- Encourage health care insurers to implement policies that enable caregivers to maintain their insurance coverage and their own health (e.g., through easy access to health screenings for stress and depression).
- Develop policies to market support services in an empathetic, collaborative manner that maintains the dignity of the caregiver and care recipient.

- Provide funding for self-help groups and respite care, two vitally needed services.
- Revise policies related to obtaining visas to make it easier for a male to enter the U.S. in order to provide care to a family member or friend.
- Develop a common definition of what constitutes a caregiver, and identify when caregiver services are eligible for third-party reimbursement.
- As a condition of funding, require that researchers have an adequate sample size of men, and provide adequate funding to support the recruitment of men into caregiving studies.

Research Recommendations

- Conduct population-based studies examining the number, characteristics, and challenges of particular groups of male caregivers, including state-specific studies.
- Reframe the basic stress-health process model as a socioeconomic model or framework that evaluates caregiving from the male perspective and includes various sub-groups, stratified by race, ethnicity, and income level.
- Examine the economic impact of male caregiving.
- Identify disparities in the health of male caregivers versus males who are not caregivers.
- Continue to examine the similarities and differences in men's and women's caregiving experiences and preventive health behaviors.
- Examine how men's caregiving experiences are influenced by differences in the following: the care recipient, dimensions of care, age/stage of the caregiver, racial/ethnic background of the caregiver and care recipient, and living situation (e.g., residential versus non-residential fathers).
- Identify factors that contribute to men's resiliency and distress in caregiving roles.
- Explore the potential rewards from male caregiving (e.g., personal growth, support).
- Investigate the reasons why men participate or fail to participate in caregiving services.
- Evaluate the impact of interventions designed specifically for men, including those based on differences in the care recipients, the relationship between caregiver and care recipient (e.g., siblings, parent-child), stage of the caregiving experience, and the nature of the intervention (e.g., home skill training, technology interventions, support groups).

- Test interventions with different racial and ethnic groups of male caregivers.
- Compare the impact of state policies that provide caregiver services (e.g., those supported by the National Family Caregiver Support Program).
- Explore relationships between improved caregiver health and the health of care recipients.

Conclusion

This conference addressed male caregiving as an important, emerging public health issue. We encourage all stakeholders to work together as partners to support male caregivers, and to develop specific programs, practices, policies, and research studies that address the very real challenges these men face on a daily basis. Male caregivers need access to education, information, respite care, counseling and therapy, transportation, and health services (for themselves and for the care recipient). It is hoped that this report will provide concrete ideas about how to address the unique needs of male caregivers and recognize their significant contributions to individuals, families, communities, and society at large.

The conference featured three researchers and experts in the area of male caregiving, three male caregivers who shared their personal experiences, and a panel of professional providers who shared best practices for supporting male caregivers. Major speakers were:

Jan Greenberg, Ph.D., MSW
Professor, School of Social Work
Research Investigator, Waisman Center
University of Wisconsin-Madison, Madison, WI

James C. Bridgers, Jr., Ph.D.
Volunteer, Male Caregivers Advocacy Support
Group (MCAS)
Health Services for Children with Special
Needs, Inc., Washington, DC

Edward Thompson, Jr., Ph.D.
Director of Gerontology Studies, College of the
Holy Cross, Worcester, MA

Elmer T. Carreno, MD
Deputy Health Officer, Prince George's County
Health Department, Langley Park, MD

Laura Gitlin, Ph.D.
Director, Center for Applied Research on Aging
and Health and Professor
Department of Occupational Therapy
Thomas Jefferson University, Philadelphia, PA

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Rev. Dr. James Lyons, Chaplain
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Pastor, Adelphi Bible Church
Adelphi, MD

Mr. M. K. Lee
Son of mother with Alzheimer's disease,
Director of Community Service, Chinese
Culture and Community Service Center,
Gaithersburg, MD

Mr. Richard Anderson
Spousal Caregiver
President, Well Spouse Association
Elkins Park, PA

The conference was co-moderated by Thomas Chapman, Ed.D, MPH, President and Chief Executive Officer of The HSC Foundation, and Sally Koblinsky, Ph.D., Professor and Chair of the Family Science Department at the University of Maryland, College Park (UMCP). Robert S. Gold, Ph.D., Dean of the School of Public Health at UMCP, welcomed conference participants, and Suzanne Randolph, Ph.D., Associate Professor in the Department of Family Science at UMCP, presented a framework for male caregiving and moderated the final session identifying programmatic, policy, and research recommendations for future attention.



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The HSC Foundation is dedicated to improving access to services for individuals with special needs who face challenging health care and social barriers. The Foundation has distinguished itself by its concern for and specialization in children's medical services and urban issues, particularly in the Washington metropolitan area. An important asset is the Foundation's two supported organizations, The HSC Pediatric Center, a pediatric specialty hospital, and Health Services for Children with Special Needs, Inc., a care coordination health plan. Both have reputations of outstanding service to children and youth with disabilities and chronic illnesses.