**Caregiving Bibliography**

**For Infusion in Foundation Practice, HBSE, or Policy Curriculum**

1. **Dilworth-Anderson, P., Williams, I. C., & Gibson, R. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review. *The Gerontologist, 42*(2), 237-272.**

Using a narrative approach, 59 peer-reviewed caregiving articles published between 1980 and 2000 were reviewed. The authors synthesized current research and identified knowledge gaps in order to inform future caregiving research, particularly with regard to race, ethnicity, and/or culture. The results showed varied caregiving experiences and outcomes across racial and ethnic groups. However, non-theoretical approaches, nonprobability samples, and inconsistent measures among studies have limited understanding of caregiving among diverse populations. The authors recommend strengthening theoretical and methodological rigor as well as providing more attention to issues such as acculturation, assimilation, and cultural values, beliefs, and norms.

1. **Feinberg, L. (2013). Keeping up with the times: Supporting family caregivers with workplace leave policies. *Insight on the Issue, 82*. In Brief, 207. AARP Public Policy Institute.**

This brief examines the current status of family caregiving leave and cites five key factors to be considered: 1) increase in women’s labor force participation, 2) aging of the workforce, 3) growing demand for eldercare due to an aging population with multiple chronic conditions, 4) increase in the number of men who are family caregivers, and 5) fragmented and complex health care and long-term services and supports (LTSS) systems. The author suggests recommendations such as expanding Family and Medical Leave Act (FMLA) coverage, protecting workers in businesses with fewer than 50 employees, and family-friendly and flexible workplace policies.

1. **Feinberg, L., Reinhard, S.C., Houser, A., & Choula, R. (2011).** Valuing the invaluable: 2011 update the growing contributions and costs of family caregiving. ***Insight on the Issues, 51*, 1-16. AARP Public Policy Institute.**

This report provides the most current data on national and individual state estimates of the economic value of family care. It also discusses the contributions of caregivers and details the costs and consequences of providing family care. It concludes with some policy recommendations to better support caregiving families such as family-friendly workplace policies, a person- *and* family-centered care plan, and improvements to the Family and Medical Leave Act (FMLA).

1. **Gibson, M.J., Kelly, K.A., & Kaplan, A.K. (2012). *Family caregiving and transitional care: A critical review*. National Caregiver Alliance.**

This paper focuses on family caregivers’ perspectives. It reviews current research and stresses what is needed in order for family caregivers to effectively partner with professionals during the transition across caregiving settings (e.g., hospital to home). Promising approaches and tools seem to exist between caregivers and professionals; however, this review finds that family caregivers deserve higher priority in most transitional care programs. It also highlights the need for greater coordination between medical services and long-term services and supports (LTSS) in transitional care. A patient and family-centered approach during transitions across settings is recommended, with a focus on including caregiver needs in a care plan.

## Ginzler, E. (2009). *Alzheimer’s caregiving: Understand the signs and get tips on coping.* Retrieved from <http://www.aarp.org/relationships/caregiving/info-04-2009/ginzler_alzheimers_caregiving.html>

This short report provides information on Alzheimer’s disease (AD), including warning signs of the disease, how to engage loved ones with AD, and AD resources.

1. **Institute of Medicine. (2008). *Retooling for an aging America: Building the health care workforce committee on the future health care workforce for older Americans*. Washington, DC: The National Academies Press.**

This report proposes a fundamental reform in the health care workforce in a concurrent three-prong approach: 1) enhance the geriatric competence of the entire workforce, 2) increase the recruitment and retention of geriatric specialists and caregivers, and 3) improve the way care is delivered. To meet the needs of the increasing number of older adults and provide them with high quality care, it is essential to develop the quantity and quality of the health care workforce. Thus, the nation needs to move quickly and act efficiently to be able to handle the needs of a new generation of older Americans.

1. **Janevic, M. R., & Connell, C. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience. *The Gerontologist, 41*(3), 334-348.**

This literature review assesses 21 studies that compared two or more racial, ethnic, national, or cultural groups on aspects of the dementia caregiving experience. The studies included samples such as African Americans, Chinese/Chinese-Americans, Koreans/Korean-Americans, Latinos, Whites, and 14 European Union countries. The results showed mixed findings in terms of coping and social support suggesting a lack of available support among minority groups compare to Whites. The authors suggest using both quantitative and qualitative methods to specify the pathways by which race, ethnicity, and culture affect the caregiving experience, as well as expanding the focus on not only the primary caregivers but also their families and networks.

1. **Kelly, K., Reinhard, S. C., & Brooks-Danso, A. (2008). Executive summary: Professional partners supporting family caregivers. *Journal of Social Work Education*, *44*(3) Supplement, 5-15.**

This article is an executive summary of the outcomes of an interdisciplinary project on family caregiving for older adults by the AARP Foundation, American Journal of Nursing, Council on Social Work Education, Family Caregiver Alliance, and Rutgers Center for State Health Policy. In order to prepare current and future professionals and help families care for older adults, this project aimed to further develop existing best practices in nursing and social work. Some strategic plans listed lay the groundwork for producing nurses and social workers with a patient- andfamily-centered care perspective.

1. **Menne, H.L., Tucke, S.S., Whitlatch, C.J., & Feinberg, L.F. (2008). Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimer’s Disease and Other Dementias*, *23*(1), 23-29.**

This paper describes how the authors develop preliminary psychometric properties of the Decision-Making Involvement Scale for individuals with dementia and family caregivers based on data from 217 individuals with dementia and their caregivers. Analyses show that the scale is reliable and can provide useful information about daily decision-making of an individual with dementia. It holds promise as a new tool to better understand the relationship between decision-making involvement and well-being of individuals with dementia and caregivers.

1. **Montgomery, R. J. V., & Kosloski, K. (2013). Pathways to a caregiver identity and implications for support services. In R. C. Talley and R. Montgomery (Eds.). *Caregiving across the lifespan* (pp. 131-156)*.* New York: Springer.**

This book chapter introduces caregiver identity theory as a conceptual framework grounded in prior research findings and discusses its potential as a useful tool to guide the delivery of caregiver support services, specifically, 1) aiding providers in understanding the sources of caregiver stress, 2) targeting appropriate caregiver support services, and 3) aiding policy makers in designing effective and efficient caregiver support systems. Caregiver identity theory also provides a framework to interpret previous research findings regarding caregiver outcomes and service use and non-use.

1. **Montgomery, R., & Kwak, J. T. (2008). TCARE: Tailored caregiver assessment and referral. *Journal of Social Work Education*, *44*(3) Supplement, 59-64.**

Care managers, nurses, and social workers struggle to efficiently use resources and provide needed assistance to caregivers without valid and reliable assessment measures. In response, in collaboration with other partner organizations, the authors developed the Tailored Caregiver Assessment and Referral (TCARE) protocol. This paper explains how TCARE was developed, its tools and six-step caregiver assessment and referral process for care managers, an evidenced-based approach to provide a systematic process for assessing caregiver needs and delivering services more efficiently.

1. **Raphael, C., & Cornwell, J. L. (2008). Influencing support for caregivers. *Journal of Social Work Education*, *44*(3) Supplement*,* 97-103.**

This article describes the challenges that health care providers face in integrating and effectively using caregivers. The authors suggest longer-range public policy approaches and address system changes to respond to caregivers’ needs. The authors’ recommendations include incorporating and supporting caregivers as part of the health care team using technology, establishing standards and guidelines, and creating a system of accountability and incentives for providers. It is inevitable that the demand for family caregivers will likely outpace the supply. Thus, national standards and guidelines for transitions between formal and informal care systems should be established and provide necessary training for caregivers, including self-managing conditions and transforming ongoing care delivery.

1. **Reinhard, S.C., Feinberg, L., & Choula, R. (2012). A call to action: What experts say needs to be done to meet the challenges of family caregiving. *Spotlight, 1*. AARP Public Policy Institute.**

This report discusses the outcomes of a forum of ten participants who have written about the challenges of family caregiving. All authors posit that there is a need for a re-examination of policies and strategies in order to strengthen caregiving families. Our costly and fragmented system of health care and supportive services is a source of frustration for family caregivers, and, thus, impedes both quality of life and care. Participating authors identified and recommended four policy and practice themes: 1) greater public education and awareness, 2) more financial relief, 3) better communication, coordination, and collaboration with health care professionals, and 4) heightened recognition of and support for family caregivers in policy initiatives.

1. **Schubert, C. C., Boustani, M., Callahan, C. M., Perkins, A. J., Hui, S., & Hendrie, H. C. (2008). Acute care utilization by dementia caregivers within urban primary care practices. *Journal of General Internal Medicine, 23*, 1736-40.**

To further knowledge on the impact of stress on the physical and mental health of caregivers of people with Alzheimer’s disease (AD), this paper measured 153 AD patients’ degree of cognitive impairment and their caregivers emergency department (ED). Results indicated that caregivers’ acute care utilization was associated with their level of depression and the patients’ behavioral and psychological symptoms and functional status. In order to improve the health of AD caregivers, primary care systems should provide more resources to manage the functional, behavioral, and psychological symptoms related to AD patients.

1. **Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, *44*(3) Supplement, 105-113.**

This article reviews the literature on the physical and mental health status of family caregivers over the past three decades. The summary includes findings on predictors of physical and mental health outcomes, positive and negative effects of caregiving, and moderating factors. The authors conclude by suggesting that the needs of caregivers should be integrated into the planning and delivery of health care and urge nursing and social work researchers to develop interventions that are designed to maintain and enhance the health of caregivers.

1. **Van Houtven, C. H., & Norton, E. C. (2008). Informal care and Medicare expenditures: Testing for heterogeneous treatment effects. *Journal of Health Economics*, *27*(1)*,* 134-156.**

This article examines the effect of informal care on Medicare expenditures both for care provided by children and by the source of informal care (sons vs. daughters, children vs. others) and recipient characteristics (marital status). The results showed that informal care by children reduces Medicare long-term care and inpatient expenditures for single older adults. However, informal care proved less effective for married recipients and there were no differences in effectiveness between daughters and sons.

1. **Whitlatch, C. J., Piiparinen, R., & Feinberg, L. F. (2009). How well do family caregivers know their relatives’ care values and preferences? *Dementia*, *8*(2), 223-243.**

Caregiving requires an understanding of care recipients and their caregivers’ values and decision-making, which can be complicated and stressful. This study examines the psychometric properties of the Values and Preferences Scale (VPS) and compares the responses of 267 persons with cognitive impairment with their caregivers’ responses. The results show that caregivers had a good sense of care recipients’ preferences but often underestimated the importance of certain values and preferences. Findings suggest that practitioners should incorporate the VPS assessment with persons with cognitive impairment and their caregivers.

1. **Wisensale, S.K. (2009). Aging policy as family policy: Expanding family leave and improving flexible work policies. In R. Hudson (Ed.), *Boomer bust? Economic and political issues of the graying society* (pp. 253-270). Westport, CT: Praeger.**

This chapter discusses four questions: 1) Who are the family caregivers of the elderly and how do their experiences affect their lives? 2) What are the strengths and weaknesses of the public policies for family caregivers? 3) How has the private sector responded to the challenge of employees who are elderly family caregivers? and 4) What strategies and recommendations should be put into place to improve family leave and flexible work policies? The author acknowledges and contends that family-friendly policies such as services under the Older Americans Act and Title XX should be broadened, tax credit programs should be expanded, and the Family and Medical Leave Act should include a wage replacement and be made more accessible to more workers.