Increasing Capacity for Family Care
A Research Opportunity

November is National Caregiving Month, and an annual opportunity to recognize and celebrate the contributions that family caregivers make to the health of our nation. They provide more than 80% of long-term care to frail older adults, with an estimated value of $470 billion annually (AARP Research, 2016). Importantly, they make it possible for older adults with serious illness and cognitive and functional deficits to remain at home, in the place of their choice. Yet, family caregivers are largely invisible in the health care system; much remains to be understood about their experience and their needs, and public recognition and policy fall short of providing adequate support for this vital role.

One in five American households is involved in a wide range of caregiving activities that vary in their intensity (National Alliance for Caregiving & AARP, 2015). In 2015, AARP conducted a national survey of family caregiving and found that many family caregivers struggle with tasks that nurses typically perform, referred to as “medical/nursing tasks” (Reinhard, Levine, & Samis, 2012). These tasks include management of medications; dressing changes; handling equipment, such as oxygen tanks; and managing incontinence. Family members typically coordinate complex, fragmented, and even contradictory advice from multiple providers and institutions. Sometimes the need to provide care begins abruptly, immediately following a hospital stay; in other situations, the needs evolve slowly over time, gradually taxing the capacity of families to manage increasingly complex care.

The demands of family caregiving have implications for the mental, physical, and financial health of those providing this vital service. The stress associated with caregiving can go unrecognized by clinicians and threaten quality of life and well-being for care recipients and caregivers.

As the United States becomes ever more diverse, greater attention must be paid to the heterogeneous needs of families whose cultural background must be considered in supporting their caregiving. A recent review of research on multicultural family caregiving identified gaps in the evidence base for interventions and a limitation in the availability of approaches to support family caregivers in culturally sensitive ways (Apesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2016). This review revealed that over the past 30 years, the majority of studies in multicultural communities have been descriptive and cross-sectional. It identified gaps in the literature, including: a dearth of longitudinal studies; a focus on the individual despite the clear importance of community and culture; the lack of interventions to mobilize and sustain the caregiving network, improve communications, and resolve conflict; and limited research on the potential of technology to enhance caregiver effectiveness and well-being. Similar limitations exist in research within the lesbian, gay, bisexual, and transgender community, with little understanding of the implications of discriminatory policies in late life, the dynamics of family networks of choice, and availability of caregivers among a community with high rates of living alone in late life (Fredriksen-Goldsen & Hooyman, 2007; Stein, Beckerman, & Sherman, 2010).

The recent report “Families Caring for an Aging America” by the National Academies of Sciences, Engineering, and Medicine (NASEM; 2015) outlines a series of recommendations to improve family caregiving capacity. In particular, Recommendation 1-g reads, “Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes” (NASEM, 2015, p. 13).
This call, and the requests for proposals it will generate, offers a timely opportunity for gerontological nurse scientists to focus efforts on expanding foundational knowledge about family caregivers, their experiences, and their needs and to design and test interventions across various health conditions, settings, diverse populations, and time. Research is also needed to establish best practices to prepare family caregivers for delivering care across the trajectory from diagnosis to end-of-life. The development of culturally appropriate approaches will depend on deeper understanding of the heterogeneity within populations (e.g., Latino, Asian American, Native American) and expanding the conceptual models for research to include relevant constructs such as reciprocity, family development/dynamics, feminist ideology, stigma/discrimination, and sociological theories.

Gerontological nurse scientists have great potential to make a difference in this field and to shift the culture from emphasizing siloed activities of hospitals and clinics to a health care system that emphasizes healthy aging and supports person- and family-centered care in the community. Leaders in long-term care policy and practice are actively seeking alternatives that meet the needs of older adults and individuals with disabilities in the least restrictive environment possible and involve collaboration among consumers, nurses, and direct care workers to provide affordable and high-quality care (Young & Siegel, 2016). We can improve the capacity of health care professionals and health care systems to recognize the role that families play in health care delivery, and partner effectively to provide community resources that assure quality care across the continuum. Gerontological nursing research can lead the way.

REFERENCES


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