Emerging Issues in Family and Individual Resilience

Whitney A. Bailey
Amanda W. Harrist *Editors*

Family Caregiving

Fostering Resilience Across the Life Course

Springer

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Series Editors
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Preface

It is projected that those 65 years and older will comprise 20% of the US population by the year 2030, with the fastest growing segment being those 85+ years (CDC, *The State of Aging and Health in America 2013*). Approximately 92% of older adults have at least one chronic disease, and 77% have at least two (NCOA, 2017). While medical technology can enable us to live longer, it does not protect us from associated illnesses such as cancer, cardiovascular disease, and musculoskeletal disease. The experience of exceptional longevity (i.e., living >100 years) is increasingly common. Yet, quality of life is not maintained. *While the demographic research is informative and vast, it is not enough to simply know we are living longer with greater likelihood of diseases.*

Providing care for one another has been at the heart of family functioning since the beginning of time. From an early age, individuals are socialized to interact with one another based on social rules, cultural norms, developmental expectations, and family meaning. Governmental rules and policies are central to the ways family and kin members function in helping one another. A key element to the ways in which state and federal policies shape caregiving in the Unites States includes "the Caregiver Assumption" (Bailey & Gordon, 2016). This refers to the expectation that a family will care for its members during acute and chronic health challenges. This is magnified by a system that prioritizes home and community-based services (HCBS) over institutionalized care. On the surface, this value—keeping people at home as long as possible—is shared by governmental systems and families alike. Yet, implementation of HCBS is done at the expense of family and kin caregivers, their health, financial futures, and other relationships. Because of the way we do caregiving in the United States, caregivers are at greater risk for providing care well beyond the scope of their abilities, increasing risk of injury (to themselves or their loved ones), which then perpetuates the cycle of risk and need for care. Family caregiving is truly a public health crisis, not only because it is inherently demanding but because of the *way* we provide care. Consequently, service and support of elders and their family caregivers is a critical public health issue. *We have known the challenges for decades, yet it is not enough to know the challenges.*

This volume seeks to provide those in the human sciences and related fields a base of topical chapters related to the caregiving experience. Resilience as a process and an outcome is a common theme throughout. Each chapter identifies the risks present in caregiving situations, while offering tips and resources for care families. So often, care families do not know where to start. The National Alliance for Caregiving and AARP's Public Policy study (2015) revealed that 84% of caregivers need more information and training to care for their loved ones. Simultaneously, many professionals do not feel equipped to assist because, with rare exception, the primary and higher education systems have failed to prepare the workforce to serve this burgeoning need. It's not as if we didn't see it coming. Yet, this volume was born out of the belief that even professionals who do not identify with the field of "Gerontology" or "Aging Studies" have the opportunity to help care families. After all, with 84% of caregivers reporting a need for more information and training in their care roles, surely each person who is reading this can do something to fill that gap. *It is not enough to say "it isn't my area."*

The opportunity now lies with us to address this public health crisis, utilizing the family resilience framework as a guide. With the passage of the CARE Act in more than 20 states, elected officials and the aging network are showing signs that they are mobilizing and primed for change in this area. Our opportunity lies in knowing what shapes caregiving experiences in our respective states and then responding: through education, advocacy, engagement, intervention, or any domain for that matter. Whether you are an advocate, researcher, educator, or practitioner, there is a need to improve the ways caregivers understand the system, access the system, and do the business of caregiving. Countless studies have shown us the risks of providing care, with little focus on protective processes. Utilizing the resilience model allows us to change the perspective from one of disadvantage and hardship to a strengths-based approach. Eighty-four percent of caregivers report needing more information and training in their care roles (2015). *We know enough to know the need. We know enough to know the consequences are life changing. Find your sphere of influence and go!*

Stillwater, OK, USA

Whitney A. Bailey
Kristopher M. Struckmeyer

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Oklahoma State University's Center for Family Resilience (CFR) hosts an annual *Chautauqua: Conference on Family Resilience*. The goals of the conference are (a) to bring together distinguished and rising scholars from diverse disciplines to discuss cutting-edge work focused on one annual theme within the broader area of family resilience research, and (b) to foster a translational approach within the study of resilience, such that practical applications for family health and well-being can be developed from basic resilience research. This includes development of action steps in conjunction with community stakeholders. The papers presented at each year's Chautauqua are the core of the chapters that comprise the respective volume in our *Emerging Issues in Family and Individual Resilience* series. We would like to thank the many people involved in planning and hosting the 2016 Chautauqua. These include OSU Human Development and Family Science (HDFS) doctoral students Zach Giano, Amy Huffer, Rebecca Hubbard, Ashley Kimble, Todd Spencer, Erin Seseman, Julie Staton, and Brooke Tuttle, who helped facilitate the Chautauqua discussion sessions and host the authors' dinner, and Kris Struckmeyer, who coordinated transportation; HDFS staff, especially Rita Ryan, who coordinated financial issues; and Dr. Christine Johnson, Lisa Smith, and Tia Claybrook, who helped with the many details of conference planning and implementation.

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We also acknowledge and are appreciative of the many resilient caregivers in our community and worldwide who give their time and love to family members in need every day. We dedicate this volume to them.

About the Series Editors

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Stephan M. Wilson is a Ph.D. graduate in Child and Family Studies from the University of Tennessee, Knoxville. He is an NCFR Fellow, Fulbright Fellow, Regents Professor at Oklahoma State University, Legend recognition of the American Association of Family and Consumer Sciences, and has numerous teaching, research, and community engagement recognitions. His areas of expertise include cross-cultural family science and adolescent social competence.

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Chapter 1
Family Resilience and Caregiving

Carolyn S. Henry, Rebecca L. Hubbard, Kristopher M. Struckmeyer, and Todd A. Spencer

Family caregiving occurs as one or more family members provide care to at least one other family member defined by the family or professionals as requiring assistance in at least one key domain of life (Walker, Pratt, & Eddy, 1995). Over time, caregiving occurs in most families as challenges in one or more areas of well-being such as physical, cognitive, or emotional well-being. In addition, caregivers often become informal case managers who coordinate care across multiple settings and providers, maintain interpersonal contact and advocacy with multiple care providers. Family members may gradually drift into, actively choose, or quickly accept caregiving during a crisis (Bailey & Gordon, 2016; Johnston, Bailey, & Wilson, 2014; Qualls & Williams, 2013). As demands increase through the daily hassles and new responsibilities of caregiving, on-going family relationship patterns require change, often involving more frequent and intense family interfaces with proximal (or close) ecosystems including medical and social services (see Table 1.1). We use the terminology of "care recipient" for individuals receiving care and "caregiver" for individuals caring for care recipients, recognizing that both caregivers and care recipients have a sense of self and family beyond these roles. In fact, individuals can be mutual caregivers and care recipients such as when spouses provide care to each other. Caregiving burden arises through ongoing daily hassles, difficult decisions, sacrifices, and other demands that increase the risk for stress, burnout, and declines in caregivers' health, self-care, and the ability to fulfill other life roles (Zarit, Reever, & Bach-Peterson, 1980). The unique combination of caregiver burden in specific

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Table 1.1 Progression of dementia: challenges for care recipients, caregivers, family adaptive systems, and family-ecosystem interface

	Stage of dementia			
	Mild disease progression	Moderate disease progression	Severe disease progression	Nearing death and grief
Challenges for care recipients	Loss of words	Unable to do simple math	Significant confusion	Loss of ability to respond to others (loss smile, eye contact, holding head up, speech)
	Forget names	Forgets some life history details	Behavior problems	Loss of ability to interact with environment
	Difficulty planning or organizing	Decreased ability in short term memory	Loss of speech	Needs help with all ADLs
	Begin short term memory loss	Difficulty managing finances or paying bills	Significant personality changes	Loss of bodily functions (possibly including the ability to swallow)
		Progressing to	Unable to recognize faces	
		Significant confusion	Needs significant help with ADLs	
		Difficulty in recall of simple information (e.g. their phone number)	Cannot remember most of personal history	
		Difficulty dressing weather appropriate	Loss of bowel and bladder control	
			Difficulty expressing needs	

Challenges for caregivers	Balancing help with autonomy	Balancing help with autonomy	Balancing help with autonomy	Understanding and accepting imminent decline and death process
	Understanding the diagnosis	Understanding the diagnosis	Understanding the progression of the disease	Preparing for death transition
	Adapting to changes and partner's decline in mental abilities	Understanding progression of the disease	Adapting to changes and partner's mental and physical decline	Coordinating care and family or ecosystem assistance
	Begin assisting and taking over financial responsibilities for care recipient	Taking over previously held responsibilities of care recipient	Adjusting to changes in relationship	
		Adapting to changes and partner's decline in mental abilities	Coordinating care and family or ecosystem assistance	
		Adjusting to changes in relationship		
		Coordinating care and family or ecosystem assistance		
Challenges for family adaptive systems	Potential changes in FES and FMS	Potential challenges in FES, FMS, FCS, and FMNS[a]	Likely challenges in FCS and FMNS	Likely challenges in FCS, FMS, FES, and FMNS
			Potential challenges in FES and FMS	

(continued)

Table 1.1 (continued)

	Stage of dementia			
	Mild disease progression	Moderate disease progression	Severe disease progression	Nearing death and grief
Challenges for family-ecosystem interface	Medical care	Medical care	Medical care	Medical care
		Social system support	Social services	Social system support
			Social system support	Ancillary services
			Ancillary services	Hospice

Notes: Families involved in caregiving for family members with dementia share the experience of progression of the condition according to individual pathways that are somewhat predictable, yet highly individualized in timing and intensity. The progression of dementia symptoms is progressive in the overall trajectory (National Institute of Health, 2016)

[a]The five stages in this model are based on coalescing existing stages of dementia (Alzheimer's Association, 2016; Alzheimer's Society, 2016; Morris, 1993; National Institute on Aging, 2016; Reisberg, 1988) that range from three to seven stages. This composite model describes challenges for care recipients, caregivers, family adaptive systems, and family-ecosystem interfaces. This guide shows general trends in progression whereas in reality, each person with dementia progresses through individualized stages

[b]*FES family emotion system*, *FMS family meaning system*, *FCS family control system*, *FMNS family maintenance system*