Family Health and Care of Older Adults:
Universal Solutions to Unique Caregiving Challenges

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Introduction
In 2002, I published an article in Michigan Family Review about taking care of elderly parents, a literature review hot off the press of a newly earned PhD in nursing. My dissertation research unexpectedly coincided with the “lived experience” of taking care of my own suddenly and seriously ill 80 year-old mother. Well, not really all that unexpected—after spouses, the most likely primary caregiver of an older adult was (and still is) an adult daughter. Still, I was taken aback when the demand hit home. My distraught feelings then didn’t come close to the sympathetic, earnest calm with which I had regarded the phenomenon from my ivory tower. Nor did they match the confident reassurances that I had dispensed to the worried families of patients throughout years of clinical practice. In short, literature, dissertation, and personal experience confirmed that parent care could be hard and stressful.

Now, for a fifteen-year postscript to the 2002 article, I face a different lived experience, but still one typical of a growing number of the elderly. Many adult women belong to the “sandwich generation” (Miller, 1981), meaning they are women in the middle—concurrently taking care of aging parents and of their own dependent children (Brody, 2003). When I took care of my mother, I was a member of the sandwich generation alright but, more accurately, a member of the open-faced sandwich generation (Abaya, N.D.). That is, I was pressed between demands of parent care and career, but without that extra layer of my own children. Now, I look in the mirror and see my aged mother. However, my mother had me and three other children. Facing my own seniority means wondering who will care for me. Who will take on the roles that I and my siblings assumed for our mother?
In this article, I examine the situation of older adults like me who do not have adult children. I consider potential solutions to my personal situation informed by recent literature and 40 years of nursing experience across a wide variety of practice settings—from hospital to home care, nursing education, policy and research. First person narratives and recommendations by gerontologists are incorporated from a special issue of the Gerontologist ("Aging: it’s personal"), in which scientists and gerontologists applied their professional identities to their own personal experiences with aging (Pruchno, 2017). This essay begins with examining the special case of caregivers for childless elders and concludes with recommendations for health systems reform organized according to a lifespan family systems perspective on intergenerational support needs and framed within an emergent model for public health and disability (Drum, 2009).

Demographic Realities of Aging Societies, or “Honey, I Shrunk the Family!”

In 1989, Disney studios produced a hit movie called “Honey, I shrunk the kids” in which an eccentric inventor creates a machine that accidentally turns his children into miniatures. The movie spawned a few sequels with similar titles and a TV show. The movies were fictional, of course, but real events of prolonged life span and reduced fertility have led to the shrinking of American families, a trend seen worldwide in industrialized countries (National Institute on Aging [NIA], 2011).

After World War II, people in the USA turned attention to raising a family and the birthrate soared during the infamous “Baby Boom”. Meanwhile, improved health and living conditions changed prospects for a long life in industrialized countries, raising the average life expectancy from 50 years in 1900 to 80 years in 1980 (NIA, 2011). The increase in life span and subsequent years of old age dependency was balanced by the availability of many adult children able to help (Redfoot, Feinberg, & Houser, 2013), but not for long. The total fertility rate (number of children per female across her lifespan) declined from a high of 3.8 in the late 1950s to less than 2 children in 2010 (Mather, 2012). In the US, the proportion of the population aged 65 and older has grown from eight per cent in 1950 to 14 per cent in 2012, and is predicted to reach 20 % by 2030 (less than 15 years away from now) (Redfoot, Feinberg, & Houser, 2011). The number of people aged 65 and older who will be living alone and who are also without living children or siblings will increase from 682,000 in 1990 to 1.2 million (Stone, 1999). Childlessness among older populations may increase up to 21% by 2040, when I would be 87 and almost 50% of my age-related peers would have only one or two children (Johnson, Toohey, & Weiner, 2007). The risk of becoming unmarried and childless, or with children out of contact may be as high as 22.6% (Carney, Fujiwara, Emmert, Liberman, & Paris, 2016).

I am not yet an elder orphan, the term used to describe older adults without children, spouses, or partners (Painter, 2016; Carney et al. 2016), even though my own family is shrinking, with all parents, parents-in-law, and their siblings (our aunts and uncles) having passed on. My older siblings and siblings-in-law are for the most part independent despite accumulating chronic conditions. Some of them have adult children and there are a few young grandchildren. There
is research to show that—not surprisingly—older adults without children turn to other family members and/or non-kin for help. While the majority of family caregivers are spouses, adult children, daughters- or sons-in law, approximately 24% of family caregivers fit another category that includes siblings, nephews or nieces (Schultz & Eden, 2016). Still, siblings of older adults are likely to be in the same age bracket as the care recipient and subject to similar risks of aging. Nephews and nieces—with a shrinking sibling pool themselves to rely on for help—may have more than two sets of older adult relatives (i.e., parents, parents-in-law, and aunts/uncles).

Shrinking family size is not completely compensated for by age-related peers or other relatives and affects the pool of caregivers available to any older adult. Since paid caregivers are often needed to augment the labor of family and friends, it’s important to include them in estimates of caregiver supply. Using a population-based method, Redfoot, Feinberg and Houser (2013) calculated a “caregiver support ratio” based on the number of potentially available caregivers for the likely number of care recipients, taking into account family and paid help. Both groups were based on age. Caregivers (e.g., adult children, spouses, and paid help) were 45-64 years old, and care recipients were 80 years and older. From 1990 to 2010, the Baby Boomers swelled the ranks of caregivers producing a caregiver ratio of 6.6 to 7.2 caregivers per older adult. But that number shrinks to 6.1 in the 2020s, and drops to 4.1 caregivers per older adult in 2030 (OUCH! There I am again on the cutting edge at 78 years old!). Due to population aging, a caregiver shortage looms on the horizon.

Preparing for Dependency to Preserve Autonomy and Protect Caregivers

So how do I prepare myself and my caregiving network for the future? Laditka (2017) tells the story of her own father’s transitions to care which maintained autonomy by his being involved in decision-making about care options. She organized her approach according to the research of Loe (2011, cited by Laditka, 2016) who found that older adults who learned how and when to ask for help actually created more personalized care arrangements and maintained meaningful lives of dignity. Laditka was ready to help her father—when he was ready to accept that help. Help was a negotiation based on preferences, resources, and abilities. Laditka’s father’s transitions from independent living in a New York apartment to a senior community in North Carolina were anticipated and eased by his daughter (Laditka), who was available to assist as the father was ready due to increasing frailty.

Someone without children or other primary caregiver would either need to find a friend or extended family member, or an employee (e.g., a geriatric case manager) for comparable guidance in later life. Elder orphans—like all elders—are advised to engage in health promoting behaviors, to get their affairs in order, to down-size and de-clutter, to identify and nurture supports such as durable powers of attorney, health care decision proxies, to make realistic assessments of abilities, and to get familiar with community supports and options (Ianzanito, 2016; Painter, 2016).
System Pitfalls for Elders and Caregivers

Sadly, despite the best-laid plans, elders and their caregivers often face enormous challenges when health fails. Numerous studies and first person accounts point to problems in the health care system itself. Elders, the chronically ill and disabled, and their caregivers must navigate a disorganized, costly and confusing system (Kane & West, 2005; Kane, 2011; Reinhard, 2004). For a special issue of The Gerontologist (2017), scientists and practitioners were invited to apply their professional identities to their personal experiences with aging. Nearly half of the resulting articles were about challenges experienced as family caregivers of older adults (Pruchno, 2017). In addition to the day-to-day demands of meeting a person’s needs, older adults and their caregivers faced a disjointed health care system, wherein the coordination of care, and navigating between the acute care and long term care systems resulted in enormous frustration. High quality care was elusive: caregivers told of catching dangerous medication errors, averting inappropriate treatment, and struggling to find appropriate care, all from a state of perpetual anxiety and exhaustion (e.g., Fredman, 2017; Kaiser & Kaiser, 2017; Moon, 2017; Taylor & Quesnel-Vallee, 2017).

Urging healthy self-care is a common approach toward the stressed caregiver (e.g., Tarantine, 2014). In part to prevent the burden of receiving or giving care, Rowe and Kahn advanced the popular concept of “Successful Aging”, targeting and charging individuals to live more healthily (Rowe & Kahn, 1997). Better health habits would lead to less disability and disease, and reduce caregiving demands. Strengthening the individual makes sense, especially given that many stressors are beyond personal control. However, personal fortitude weakens in the face of the unrelenting frustration encountered by many older adults and their caregivers, leading Rowe (2015) to call for the successful aging of societies. Rowe described the recommendations of the MacArthur Foundation Research Network to evaluate social systems and promote policies leading to a multigenerational, family and life-course perspective that supports aging.

Key Principles: Families, Generations, Life-span, Housing and Specialty Care

Family health is “the collective emotional and physical health of a family” (Ziemba, 2002). Family is defined as the network identified by the older adult of friends and relatives. In short, a patient’s family consists of whomever they say. Within such families, exchanges occur of social, emotional, physical and/or financial support. A function of the family is to balance the needs and resources among family members (including intergenerational members) to maintain the health of individual members and of the family unit.

Research on caregiving is still focused on an individual “primary” caregiver, and not on the caregiver network. Thinking about family systems forces a focus on networks. For example, relevant policy changes could include extending eligibility for family leave to other members of the family, including nieces, nephews, and siblings (Schulz & Eden, 2016). This would allow childless elders to rely on a care network in ways that allow their sandwich status to become less important.
The current US health care system is a threat to intergenerational relationships in families and intergenerational justice within society. The first step to promote family health is universal health care coverage. Adult children face a more uncertain future if they have had to forego employment or health insurance in order to provide care to a parent, or to other family members. Caregivers should not be forced to choose between taking care of their own health, or that of parents, or children, or other relatives. This injustice extends to paid caregivers. The backbone of this sector is composed of direct care workers (more commonly known as nurses’ aides), who receive such low wages and benefits that they themselves do not have any health care insurance, despite the hazardous workload. The quality of elder care would increase if those paid caregivers could rely on health care coverage, too (Better Jobs Better Care, 2004).

A lifespan approach extends the concept of “aging” beyond the seemingly-sudden crossover into the golden years, and looks holistically at the needs of people from birth to death. Many challenges of taking care of someone are similar no matter what their age or relationship to the caregiver. Even though older adults form the largest group, over a third of long term care recipients are younger adults or children with disabilities (Weiner & Sullivan, 1999.) Normalization rather than the pathologizing of aging and disability emphasizes inclusion and the realization that the able-bodied are merely temporarily so (disability activists call them “temporarily able-bodied,” or “TABs”). Normalization means confronting the dependency/independence dialectic and shaping supportive social and built environments.

**Integration of Medical care, Long Term Care and Public Health**

The dominant philosophy in the US is obsessed with what has been termed a medical model of care (Ziemba, Perry, Takahashi, & Algase, 2009). A medical model emphasizes acute care interventions, medical diagnosis, and treatments of medicine and surgeries, most typically administered in doctors’ offices and hospitals. Many miracles of modern medicine are invaluable but the model is inadequate when long term care is needed because of chronic illness or disability. “Nursing home” is what most people think of when they hear the phrase “long term care.” However, there are many alternatives to nursing homes. Universal health care is only a partial solution because is still represents a medical, treatment-based model of care. For long term care, the medical model represents a bias toward institutional care (i.e., traditional nursing home) and lack of autonomy (Wiener & Sullivan, 1999). To signal the change to a social model, disability advocates prefer the term “long term services and supports” (LTSS).

Drum and colleagues (2009) criticized policies and practices around disability that foster isolation and despair. Such policies contribute to excess disability, which is helplessness or inability to perform some activity due to restrictive conditions rather than due to the disability itself. A modern public health approach to disability has evolved from a focus on prevention of disabling injuries to one based on shaping the socio-political and built environment. Policies and attitudes shape the creation of a social environment for inclusion rather than isolation. In turn, key features of the environment such as accessible
housing, stores and transportation are fostered. Universal design can facilitate inclusion and social participation for many individuals across society (Steinfeld & Maisel, 2012; Universal Design, 2016). Integrated approaches to transportation such as “Complete Streets” (Smart Growth America, 2017) can promote physical exercise and can benefit not only the elderly, but also pedestrians, parents pushing baby strollers, and adults and children using bicycles or wheelchairs.

Aging services have already benefitted from social movements to improve the lives of people with disabilities of younger age. The Individuals with Disabilities Education Act of 1990 updated earlier laws to guarantee education to children with disabilities. The Americans with Disabilities Act of 1990, more widely known for its impact on inclusion and accessibility in the workplace, formed the basis for the landmark Olmstead decision which compelled states to provide people eligible for Medicaid funded LTSS the choice to receive services in the home, rather than the previously existing default of nursing homes.

**Housing and Bringing It All Home**

Frequently, the question of how to provide or access care for older adults is inseparable from where to live. For the most part, older adults are loath to leave their homes, and prefer to “age-in-place” (Lerner, 2016). But this lifestyle might get increasingly risky or impractical, signaling a move or an increase in home support to get LTSS. Since the 1970s the aging industry has been flummoxed about labels and laws governing alternative residential options to nursing homes (Palmer, 1983). While numerous alternatives have evolved, the panoply is so confusing that few consumers and families have trouble navigating the system of independent care, housing with services, adult foster care, homes for the aged, life care continuum, and the bewildering variations on the theme of assisted living (Ziemba et al., 2009). Better definitions that clarify the differences among options are needed while blending the best of medical and social models. The unifying framework would facilitate access to both medical and long term supports and services.

The continuum of choices would range from more traditional congregate settings to community based options like “naturally occurring retirement communities” (Masotti, Fick, Johnson-Masotti, & MacLeod, 2006) and “Villages,” cooperative-type models in which neighbors band together to procure services (Butler & Diaz, 2015; Greenfield, Oberlink, Scharlach, Neal, & Stafford, 2015).

**The Unique Aspects of Aging & the Lack of Trained Providers**

Last, it is important to appreciate the unique situation of each family and each patient. Despite the similar challenges facing family caregivers of older adults and younger adults with disabilities, there are unique aspects to the aging physiology and thus a need for specialists in geriatric medicine. We readily recognize the role of pediatricians (specialists in the care of children), but it may come as a surprise to the reader that there is a persistent shortage of health care providers that specialize in geriatrics or gerontology (Hafner, 2016; IOM, 2008; Rowe, 2015). Old age is accompanied by unique syndromes, but most health care practice with adults is based on younger aged physiology and assumptions. For
example, due to declining kidney and liver function, older adults are more prone to the effects of drugs and interactions among them, and the hazards of polypharmacy. Nonetheless, prescribing patterns do not—by and large—recognize these hazards (Lavan, Gallagher, & O’Mahoney, 2016). People also assume that nurses are prevalent in nursing homes; sadly not (Hirschfeld, 2009; Wunderlich & Kohler, 2001). The majority of LTSS workers are direct-care workers with minimal training, in low-wage jobs. I just described numerous residential options for older adults, but health care providers are typically unaware of these distinctions and the limits of medical or social services available in them (e.g., Moccia, 2016).

In summary, family caregivers for older adults may be in shrinking supply due to demographic changes in fertility and family composition. But there are potentially many supports for both caregivers and older adults that could contribute to the successful aging of a family-friendly society.

Conclusion

In this essay, I abruptly changed course from mulling over the uncertainties of my particular status as an older adult without adult children to tend me in my golden years, to talk about some of the universal challenges that face family caregivers. I then switched from a dystopian assessment to a utopian vantage point, envisioning how many problems faced by families could be redressed through a positive approach and positive supports for aging. I advocated for a lifespan developmental approach in the process. I began with reflections on my expectations as a member of the “open-faced sandwich generation” of caregivers, meaning those adult children without children of their own, and arrived at the conclusion that all caregivers and care recipients have much in common.

In closing, a jingle from the 1970s plays over and over in my mind. In response to the uniform fast-food burgers of the day, Burger King™ inserted a competitive edge by offering consumer choice, expressed in song, “Hold the pickle, hold the lettuce, special-orders don’t upset us. All we ask is that you let us serve it your way” (https://www.youtube.com/watch?v=KJXzkUH72cY). With looks of amazement, family members at the counter alter their individual orders. The father says as the family of four takes their food to a table, happily concluding the ad, “Now that’s the way to do things—OUR way!”

We can share a vision with policy makers, health care providers, and the public to shape a society in which interventions and services accommodate the unique and common needs of patients and families, maximizing dignity and choice for sandwich generations of every type (including my own open-faced sandwich).

References


Burger KingTM. (1974). “Have it your way.” [https://www.youtube.com/watch?v=KJXzkUH72cY](https://www.youtube.com/watch?v=KJXzkUH72cY)


