

THE FUTURE OF FAMILY CAREGIVING

JOSEPH E. GAUGLER, PH.D.
ASSOCIATE PROFESSOR, MCKNIGHT PRESIDENTIAL FELLOW
SCHOOL OF NURSING
CENTER ON AGING
THE UNIVERSITY OF MINNESOTA





The future starts today, not tomorrow.

Pope John Paul II

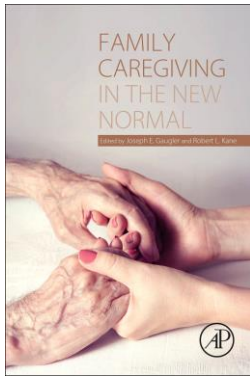
2



SPECIFIC AIMS

- The perfect storm? Some prognostications
- Challenging trends
- Navigating the storm
- Final thoughts: The importance of the personal perspective

3



<http://store.elsevier.com/Family-Caregiving-in-the-New-Normal/ISBN-9780124170469/>

4

Topic	Prognostication/Hope
<i>Changing Demographics: More Needs, More Cops</i>	<ul style="list-style-type: none"> By 2024, more political clout—and therefore services—for seniors Growing resentment on part of younger generations Greater societal emphasis on healthy aging and brain health More varied family structures and cultural backgrounds of Americans will require more creative thinking about sustainable caregiving plans
<i>Changes in Social Values</i>	<ul style="list-style-type: none"> A majority of Americans will lean pro-choice about selecting means and timing of their own deaths The term <i>palliative</i> care will disappear because palliation will be seen as part and parcel of routine health care One-quarter of states will have Aid in Dying laws Americans will accept employer discrimination against workers with poor health habits
<i>Changes in Dementia Care</i>	<ul style="list-style-type: none"> By 2024, we will no longer refer to Alzheimer's as if it is one disease. There will be broad recognition of different subtypes, as well as acknowledgment of the irreversibility of brain aging Dementia caregiver support services will be seen as more important than ever
<i>Changing Finances</i>	<ul style="list-style-type: none"> Once family as unit of care is more firmly accepted and evidence-based practices are established, government funders and insurance companies will pay for more caregiver services as means of lowering costs for health care and long-term care

5

<i>Changes in Policy</i>	<ul style="list-style-type: none"> All healthcare professionals will have more extensive training in aging and chronic care management Stipends for caregivers will slowly grow Much greater regulation, standardization and scrutiny of funded services, especially home health care
<i>Changes in Research</i>	<ul style="list-style-type: none"> States will make funding for caregiver support programs contingent on adoption of evidence-based protocols Research will increasingly focus on use of technology
<i>Changes in Practice</i>	<ul style="list-style-type: none"> Increased emphasis on cost containment Collaboration for greater educational, clinical reach Co-location of healthcare and social service professionals, as well as insurance representatives Deprofessionalization Boom in home-based care management
<i>Changes in Technology</i>	<ul style="list-style-type: none"> Home and biological monitoring will become standard by 2024 Caregiver interactions with healthcare/social service teams will be mostly online through portals Caregiver support programs will make much greater use of web and telephone
<i>Changes in Work</i>	<ul style="list-style-type: none"> Elder care will be seen as an increasingly important human resource issue for corporate America Vocal Baby Boomers will demand greater flexibility and support Area Agencies on Aging will create information/consultation packages (especially regarding dementia care and work-life balance) to market to local businesses
Source: Adapted with permission from Barry Jacobs, PsyD.	

6



CHALLENGING TRENDS

- Caregiver supply and diversity

7

Caregiver Support Ratio

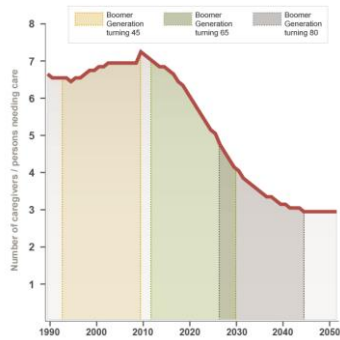


FIGURE 18.1 The caregiver-care recipient gap. Copyright the American Association of Retired Persons, 2011. Used with permission.

8



TABLE 6.2 Percent of Women 55 and Older in the Labor Force: 1992–2022

	1992	2002	2012	2022
55 and older	22.8	28.5	35.1	37.5
55 to 64	46.5	55.2	59.4	64.3
65 and older	8.3	9.8	14.4	19.5
75 and older	2.8	3.5	5.0	8.0

Source: U.S. Census Bureau, 2009 Population Estimates, National Population Projections, 2008.

9



CHALLENGING TRENDS

- Economic concerns

10

TABLE 8.3 Summary Statistics

Variable Description	2006		2010	
	Caregivers (N = 2693)	Noncaregivers (N = 9899)	Caregivers (N = 3796)	Noncaregivers (N = 11,458)
Wealth and debt*				
Net worth	628258.70 (262556.10)	772530.60*** (349844.40)	520419.30 (183389.50)	613658.80** (259960.10)
Household income	109157.20 (57146.25)	109384.70 (67066.95)	86226.28 (57037.57)	99198.99*** (67736.05)
Disposable income ^b	79115.13 (48574.31)	79722.84 (47751.88)	64159.47 (48881.94)	73126.71*** (55099.03)
Earnings from pensions or annuities	4631.38	4819.54	2908.07	3683.32**
Own a home	0.85	0.89***	0.81	0.86***
Total debt	74617.37 (111515.62)	77915.84 (115446.08)	75749.66 (11630.31)	83042.23 ^c (20969.7)
Debt to disposable income ratio	4.05	23.71	1.76	3.80
Family income below poverty threshold ^d	0.10	0.06***	0.11	0.07***
Out-of-pocket medical costs	3275.01 (1497.03)	3416.69 (1727.343)	3447.33 (1546.768)	3461.20 (1667.091)

11



CHALLENGING TRENDS

- Politics/Policy challenges
 - The rebalancing movement
 - Ideological divides
- Chronic disease
- Translating evidence-based programs

12



- Technology solutions

TABLE 12.1 Smart-Home Functionalities and Implications for Caregiving

Functionality	Definition	Implications for Caregiving
Physiological monitoring	Collecting and processing physiological measurements such as vital signs of pulse, respiration, temperature, bladder and bowel output, etc.	Providing summary data sets describing physiological status to inform care coordination, preparation of meals, and symptom management.
Functional monitoring	Collecting and processing functional measurements such as general activity level, motion, gait, meal intake, and other activities-of-daily-living	Informing potential interventions to reduce environmental elements that pose a fall risk, discerning need for assistance with personal care and daily activities
Safety monitoring	Collecting and processing measurements that detect environmental hazards such as fire or gas leak. Safety assistance includes functions such as automatic turning on/off bathroom lights when getting out of bed, facilitating safety by reducing trips and falls. Location technologies including global-positioning system (GPS)-based tracking aimed at safety also fits into this type.	Providing peace of mind for caregivers
Security monitoring and assistance	Enables measurements that detect human threats such as intruders. Assistance includes responses to identified threats	Provides peace of mind for caregivers and enables them to adjust their schedule if loved one needs to be briefly unattended
Social interaction monitoring and assistance	Collecting and processing of data pertaining to frequency of social interactions such as phone calls, visitors, and participation in activities. Social interaction assistance includes technologies that facilitate social interactions, such as video-based components that support video-mediated communication with friends and loved ones, virtual participation in group activities, etc.	Providing virtual presence for remote/visiting caregivers, informing interventions to increase social interactions and facilitating the engagement of other family members and friends who can participate in group discussions and activities
Cognitive and sensory assistance	This feature supports automated or self-initiated reminders and other cognitive aids such as medication reminder and management tools, lost key locates, etc., for users with identified memory deficits. Cognitive assistance applications also include task instruction technologies, such as virtual instructions in using an appliance. Sensory assistance includes technologies that aid users with sensory deficits such as sight, hearing, and touch	Assist caregiver with medication administration, coordination of tasks, and assistance with instrumental activities of daily living

TABLE 15.1 Listing of OHCs

OHC	Description
Care Innovations (C.I. Inc)	A company that provides informed and actionable insights into connecting providers, payers, caregivers, and consumers, and bringing the care continuum to the home (http://www.CareInnovations.com)
CaringBridge	A nonprofit organization that offers free personalized websites to people facing various medical conditions, hospitalization, and medical treatment and/or recovery. The service allows family members and friends to receive information and updates (http://www.CaringBridge.org)
DailyStrength	A social networking website centered on support groups and discussions, where users provide one another with emotional support for medical conditions or life challenges (www.DailyStrength.org)
HealthyCircles	A full featured care coordination and care management portal designed to satisfy hospital transitions of care and Accountable Care Organizations (www.HealthyCircles.com)
Healthboards	A social networking support group website consisting of Internet message boards for patients-to-patient health support, including sharing information and support on a wide range of health issues (www.Healthboards.com)
Medhelp	An American private corporation that partners with doctors from hospitals and medical research institutions to deliver online discussion boards on healthcare topics (www.Medhelp.org)
PatientsLikeMe	A patient-powered research network and research platform that connects those who have the same disease or condition and generates data to assist researchers, pharmaceutical companies, regulators, providers and nonprofits in developing more effective products, services, and care (www.PatientsLikeMe.com)
WebMD	An American corporation providing information services health care, including a symptom checker, pharmacy information, drug information, and physician blog (www.Webmd.com)



NAVIGATING THE STORM

- Person-centered care principles

19

TABLE 14.1 Principles for Provider-Directed Patient-Centered Care^a

Domain	Action	Suggested Statement/Gesture
Engagement		
1.	Makes introductions	<i>My name is Dr. Jones and I am a geriatrician who specializes in dementia care. Please tell me your names.</i>
2.	Establishes physical contact	<i>Shakes hands, hand on the shoulder</i>
3.	Maintains eye contact and posture is at eye level	<i>It is a pleasure to meet you. Is there enough light in this room?</i>
4.	Uses a calm voice	<i>Am I speaking clearly enough for you to understand me? Are you comfortable?</i>
Respect		
5.	Inquires about preferred names	<i>What would you like me to call you?</i>
6.	Ensures understanding	<i>Does what I just said make sense to you? What parts don't fit for you?</i>
7.	Provides clear explanations	<i>Let me make sure that I have been clear and I will go over this again</i>
8.	Avoids interruptions	<i>I apologize. I did not allow you to finish what you were saying. Please go on.</i>

20

Dignity		
9.	Obtains history on meaningful past events, work history	<i>What were some of the things you used to do that were most important to you?</i>
10.	Acknowledges and supports desire for independence	<i>Not being able to remember things is really frustrating. Let's figure out a way that you are able to do more things for yourself.</i>
11.	Acknowledges past accomplishments	<i>I am impressed by what you have done in your life. You have much to be proud of.</i>
Empowerment		
12.	Solicits solutions to problems	<i>How do you think I can help to make this better? What could you do differently?</i>
13.	Find common ground for problem management	<i>Let's figure out a way to do this so that everyone benefits.</i>
14.	Develop a therapeutic alliance	<i>Let's be sure that we work together on this problem.</i>

^aDubbin, Chang, and Shim (2013).

21



FINAL THOUGHTS

22



OPPORTUNITIES TO HELP: FAMILIES AND LTC PROJECTS

- Remote health monitoring for persons with memory loss and their family caregivers: The eNeighbor (see handout)
 - <http://www.nursing.umn.edu/eneighbor>
- The personal health record for persons with memory loss and their family caregivers (see handout)
 - <http://z.umn.edu/personalhealthrecord>
- Caring for a Person with Memory Loss Conference (see handout)
 - Saturday, May 30th, 8AM to 4:30PM, University of Minnesota
 - <http://www.nursing.umn.edu/memoryloss>

23



Joseph E. Gaugler, Ph.D.
 Associate Professor, McKnight Presidential Fellow
 Center on Aging, Center for Gerontological Nursing,
 School of Nursing
 The University of Minnesota
 6-153 Weaver-Densford Hall, 1331
 308 Harvard Street, S.E.
 Minneapolis, MN 55455
 Phone: 612-626-2485
 Email: gaug0015@umn.edu
 Fax: 612-625-7180

24
