

TO: Health and Public Policy Committee
FROM: Josh Serchen, Senior Analyst, Health Policy
SUBJECT: Reviewing Literature on the Impact of Informal Caregiving on Healthcare Outcomes
DATE: March 5, 2020

The first resolved clause of resolution 14-F19, *Reviewing Literature on the Impact of Informal Caregiving on Healthcare Outcomes*, was referred to the Health and Public Policy Committee for implementation with input from the Clinical Guidelines Committee (CGC) and the Ethics, Professionalism, and Human Rights Committee (EPHRC). The second resolved clause was referred to the Education Committee while the third resolved clause was referred to the Patient and Interprofessional Partnership Committee.

RESOLVED, that the Board of Regents review the literature regarding family and informal home-based caregiving as it impacts health outcomes, and summarize the evidence regarding caregiver education and training, well-being, and the impact of findings on patient outcomes; and be it further

RESOLVED, that the Board of Regents develop a strategy to inform and educate internists on the importance of and best ways to support family and informal caregivers, including existing certification programs and education; and be it further

RESOLVED, that the Board of Regents develop guidance, best practices and tools for physicians to use in consultation with patients and their caregivers that aligns with patient and caregiver needs.

BACKGROUND ON INFORMAL AND FAMILY CAREGIVING

Informal caregivers can be defined as an individual providing some form of unpaid and continuous assistance completing activities required of daily life for someone with a chronic illness or disability.ⁱ Schulz and Tompkins identify three general types of informal caregivers: children with chronic illness/disability cared for by young adult parents, adult children with mental or physical disability cared for by middle-aged parents, and older adults cared for by spouses or middle-aged children.ⁱⁱ The average informal caregiver in the U.S. skews middle-age, female, college educated, employed, and averages more than 20 hours per week in unpaid care. Estimates find that roughly 43.5 million individuals provide informal care to an adult or child, with 34.2 million of them caring for someone age 50 or older. Those providing care are responsible for a variety of activities, including emotional support, managing and assisting in medical interactions, providing transportation, completing chores and errands, managing finances, coordinating nurses and aides, providing care and assisting with hygiene, and aiding in complex medical and nursing tasks, among others. The total value of informal care is about

\$500 billion a year. With the growing senior population and resource constraints on the existing health and formal caregiving system, it is expected that the prevalence of informal and family caregiving will grow in the years to come.

Family and Informal Caregiving and its Impact on Health Outcomes and Well-Being

Vitaliano et. al conducted a meta-analysis of 23 studies to compare health indicators of demographically similar caregivers and noncaregivers, finding a marginally greater risk for health problems in caregivers.ⁱⁱⁱ Another meta-analysis of 84 articles by Pinquart and Sörensen looked at perceived differences in stress, depression, general well-being, physical health, and self-efficacy between caregivers and noncaregivers.^{iv} While caregivers had lower perceived statuses for all indicators, the difference in level of physical health was much lower than the others. Dementia caregivers tended to have larger differences than general caregivers and the relationship of caregiver to recipient and age of caregiver also impacted the magnitude of difference. Pinquart and Sörensen expanded upon their original meta-analysis by considering 176 studies looking at caregiver physical health.^v Higher levels of care recipient behavior problems, older age, lower socioeconomic status, and lower levels of informal support were most strongly associated with poorer physical health. The impact of caregiving on health was most pronounced amongst, older caregivers, those psychologically distressed caring for dementia patients, and men.

In addition to self-reported physical health status, several studies analyze differences in mortality rates in determining the impact of caregiving on health. Amongst elderly spousal caregivers experiencing mental or emotional strain, Schulz et. al finds that mortality risks were 63 percent higher compared to noncaregivers, while those providing care but not experiencing strain did not have elevated mortality rates.^{vi} Analyzing records of elderly Medicare enrollees, Christakis and Allison found that hospitalization of a spouse and the resulting caregiving was associated with higher mortality rates.^{vii}

There is a gap in the literature examining the presence of clinical psychiatric conditions arising from caregiving. However, Schulz et. al finds increased rates of self-reported psychiatric illness symptoms for caregivers compared to noncaregivers, as well as physical illness.^{viii} A review of the literature on dementia caregivers finds higher levels of depressive symptoms, clinical depression, and expression and weaker elevated levels of self-reported health, illness, health care utilization, preventive health behaviors, and cardiovascular health.^{ix} Poor psychiatric health was most associated with patient problem behaviors, income, self-reported health, stress, and life satisfaction. Psychiatric morbidity was associated with lower physical health, as well as patient problem behaviors, cognitive impairment, and social support.

Much of the literature pertaining to mental health examines the prevalence of depressive symptoms amongst caregivers. A review of the literature suggests that informal caregivers are more likely to report depressive symptoms and other psychological stressors than the general population.^x Yates et. al finds that caregiving stressors, a factor of hours of care provided and overload, resulted in increased rates of depression for informal caregivers, which was partially mediated by the quality of relationship between giver and recipient, high levels of mastery, or emotional support.^{xi} For caregivers of survivors of acute respiratory distress syndrome, health-related quality of life was lower compared to noncaregivers after accounting for age. Emotional stress was associated with lifestyle interference, lower levels of mastery, and depressed recipients of care, while caregiver well-being was associated with personal gains from providing care, mastery, and social support.^{xii} Schulz et. al found that depression, stress, and well-being in caregivers were impacted by care recipient behavior problems, physical ability, and cognitive impairment; duration and amount of care provided; age; relationship between caregiver and recipient; and sex.^{xiii} Pinquart and Sörensen conducted a meta-analysis of 228 studies looking at the associating of care-related factors with burden and depressed mood.^{xiv} Behavioral problems of care recipients was the most impactful factor and was stronger for spousal caregivers than adult children caregivers. A study of caregivers to family members with dementia found that while self-reported health was generally negatively associated with caregiving, those transitioning to heavy caregiving had more depressive symptoms and poorer health.^{xv}

Researchers have also looked at how caregiving impacts quality of life, which often stems from physical health and mental health. Metzelthin studied informal caregivers in a home and long-term institutionalized care setting, finding that those providing care at home had a lower quality of life.^{xvi} Care recipients who were male, married, more morbidities/disability, and worse mental/physical health, and caregivers who were female, younger, living with the recipient, worse health, and more burden were associated with lower caregiver quality of life. Goetze et. al found that the magnitude of physical and emotional exhaustion of an informal caregiver to a palliative cancer patient increased over time and that those with financial burden as a result of the care had the highest magnitude.^{xvii} This exhaustion was associated with psychological distress, quality of life, and sense of coherence. In a study of caregivers of patients with dementia, Takai et. al found that a caregiver's quality of life worsened as the care recipients symptoms worsened and that quality of life was most impacted by depressive symptoms, burnout, and cognitive impairment of the patient.^{xviii} Roth et. al studied quality of life amongst middle-aged and older adults, finding that caregivers reported a lower quality of life than noncaregivers and was associated with the level of caregiving strain.^{xix} Those providing high-strain care reported worse emotional and physical health, as well as fewer social contacts while those providing no-strain care report a better quality of life than noncaregivers.

Burnout and diminished quality of life for a caregiver could translate to the care provided to the recipient. Wigglesworth et. al's study on the abuse and neglect of dementia patients found that mistreatment was present in 47.3 percent of patients and found that mistreatment was associated with caregivers' anxiety and depressive symptoms, social contacts, perceived burden, and emotional status.^{xx} Similarly, Yan found that abuse of older persons with dementia by informal caregivers was associated with time spent together and caregiver depersonalization.^{xxi} Litzelman's et. al examination of the impact of caregiver's well-being on perceived quality of care for cancer patients found that patients whose informal caregivers exhibited depressive symptoms and poor self-reported health were much more likely to report fair or poor quality of care.^{xxii}

While most of the literature on the health impacts of caregiving focuses on self-reported mental and emotional health, there is some work out there examining inflammatory burden and other biomarkers of poor health amongst caregivers. Excessive production of interleukin-6 (IL-6) is associated with several age-related health conditions like cardiovascular disease, osteoporosis, arthritis, type 2 diabetes, certain cancers, periodontal disease, frailty, and functional decline. Gouin et. al found that dementia caregivers were more likely to experience stressors than noncaregivers, and that these stressors were associated with greater serum IL-6 and C-reactive protein (CRP) levels.^{xxiii} Over a period of six years, Kiecolt-Galser et. al found that the IL-6 rates increased 4 times as much for caregivers of a spouse with dementia than for those who were not caregivers.^{xxiv} Von Känel et. al similarly found that informal caregivers of patients with Alzheimer's disease had higher mean levels of IL-6 and D-dimer than noncaregivers, while CRP levels were similar.^{xxv} Gouin et. al find that the stress endured by elderly caregivers may lead to premature aging of the immune system and result in poorer response to vaccines, impaired control of latent viruses, and exaggerated production of inflammatory mediators at a level that may negatively impact health.^{xxvi} Epel et al. found that caregivers reported significantly higher rates of stress compared to noncaregivers and that the duration of time spent as a caregiver and perceived stress were associated with indicators of cellular aging like shorter telomere length, lower telomerase activity, and greater oxidative stress.^{xxvii}

However, some studies indicate that not all of the impacts of caregiving on health and well-being are negative, as Schulz et. al point out that roughly one-third of respondents tend not to report any strain or negative health effects.^{xxviii} These respondents tend to report increased sense of self-worth from helping others, more meaning in their lives, strengthened relationships, and learning new skills. Brown et. al found that those providing support to friends, relatives, neighbors, or spouse had lower five-year mortality rates than individuals who didn't help others.^{xxix} In a National Study of Caregiving survey conducted by the U.S. Department of Health and Human Services and the Urban Institute, two-thirds of informal

caregivers reported substantial positive aspects from caregiving, citing certainty that the recipient is being well cared for and a deepened relationship between giver and recipient.^{xxx} Only 10 percent reported substantial negative aspects ranging from exhaustion, strenuous workload, and lack of time. Those reporting negative aspects were more likely to also suffer from depression, anxiety, and diminished physical health.

Additionally, there are several population-based studies finding improved health indicators for the caregiving population compared to noncaregivers. Brown et. al found that amongst elderly married couples over a seven year period, those who provided at least 14 hours of care per week to their partner had lower mortality rates compared to those couples who did not provide care after accounting for care recipient characteristics and other health and demographic factors.^{xxxi} Looking at stress in elderly women, Fredman et. al found that high-stress caregivers and noncaregivers had higher mortality rates than low-stress noncaregivers over the first three years, while these rates were similar in later years. However, low-stress caregivers had lower mortality rates than noncaregivers. Similarly, a comparison of mortality rates for caregivers matched with noncaregivers with similar demographic and health characteristics found an 18 percent lower mortality rate for caregivers over a 6-year period. Longitudinal studies using national census data in North Ireland and England and Wales both found that caregivers had lower mortality rates than noncaregivers.^{xxxv}

Informal Caregiver Education and Training

There is a general gap in literature evaluating the needs and capabilities of informal caregivers. Without an understanding of caregiver training, knowledge of the disability/illness, care mastery, or competency in navigating the health care system, caregivers may be left unequipped to provide services appropriate to the needs of the recipient. Evidence suggests that access to training and resources better prepares caregivers to cope with caregiving challenges and monitor the recipient to appropriately assist^{xxxvi} and that individualized and experiential training for informal caregivers, particularly for those caring for cancer patients, is feasible, relevant, and desired.

Belle et. al conducted a study where over a period of six months, one group of caregivers were given 12 in-home and telephone sessions on addressing caregiver depression, burden, self-care, and social support and care recipient problem behaviors while the other group only received 2 brief check-in calls.^{xxxviii} Caregivers in the intervention group experienced great improvements in quality of life compared to the control group, as well as a lower prevalence of depression. Another home-based occupational therapy study, which trained an intervention group of family caregivers to those with dementia in personally customized activities, found the trainings reduced behavioral symptoms and caregiver burden.^{xxxix} A randomized controlled trial conducted by Mittelman et. al offered counselling, support groups, and other training to an

intervention group of caregivers to a spouse with Alzheimer's disease, which found that the intervention group had better self-reported health indicators and number of illnesses.^{xi}

The literature on evaluating caregiver performance in implementing skills received through training intervention, as well as their usefulness, duration of utilization, effectiveness, and quality, is lacking. In one exception, caregivers who received five home and one telephone occupational therapy sessions and were provided education, problem-solving, and adaptive equipment reported handling memory-related behaviors better, needing less assistance from others, and better affect.^{xii} Another study provided an intervention group with training on infection prevention, pain control, nutrition, and other care issues, which resulted in increased self-efficacy in the intervention group.^{xiii}

There are some indications that training caregivers may have a positive financial impact on the health care system. Caregivers who receive training have also found to result in lower total health and social care costs for patients over one year compared to those who were not trained, largely due to decreased time spent in the hospital for the patient.^{xiiii} Caregivers who were trained were also found to have less anxiety, depression, burden, and a higher quality of life.

ⁱ Roth, David L., Lisa Fredman, and William E. Haley. "Informal caregiving and its impact on health: A reappraisal from population-based studies." *The Gerontologist* 55, no. 2 (2015): 309-319.

ⁱⁱ National Research Council. "Informal caregivers in the United States: prevalence, caregiver characteristics, and ability to provide care." In *The role of human factors in home health care: Workshop summary*. National Academies Press (US), 2010.

ⁱⁱⁱ Vitaliano, Peter P., Jianping Zhang, and James M. Scanlan. "Is caregiving hazardous to one's physical health? A meta-analysis." *Psychological bulletin* 129, no. 6 (2003): 946.

^{iv} Pinquart, Martin, and Silvia Sörensen. "Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis." *Psychology and aging* 18, no. 2 (2003): 250.

^v Pinquart, Martin, and Silvia Sörensen. "Correlates of physical health of informal caregivers: a meta-analysis." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 62, no. 2 (2007): P126-P137.

^{vi} Schulz, Richard, and Scott R. Beach. "Caregiving as a risk factor for mortality: the Caregiver Health Effects Study." *Jama* 282, no. 23 (1999): 2215-2219.

^{vii} Christakis, Nicholas A., and Paul D. Allison. "Mortality after the hospitalization of a spouse." *New England Journal of Medicine* 354, no. 7 (2006): 719-730.

^{viii} Schulz, Richard, Paul Visintainer, and Gail M. Williamson. "Psychiatric and physical morbidity effects of caregiving." *Journal of Gerontology* 45, no. 5 (1990): P181-P191.

^{ix} Schulz, Richard, Alison T. O'Brien, Jamila Bookwala, and Kathy Fleissner. "Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes." *The gerontologist* 35, no. 6 (1995): 771-791.

^x Roth, David L., Lisa Fredman, and William E. Haley. "Informal caregiving and its impact on health: A reappraisal from population-based studies." *The Gerontologist* 55, no. 2 (2015): 309-319.

^{xi} Yates, Mary Ellen, Sharon Tennstedt, and Bei-Hung Chang. "Contributors to and mediators of psychological well-being for informal caregivers." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 54, no. 1 (1999): P12-P22.

^{xii} Cameron, Jill I., Margaret S. Herridge, Catherine M. Tansey, Mary Pat McAndrews, and Angela M. Cheung. "Well-being in informal caregivers of survivors of acute respiratory distress syndrome." *Critical care medicine* 34, no. 1 (2006): 81-86.

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- ^{xiii} Schulz, Richard, and Paula R. Sherwood. "Physical and mental health effects of family caregiving." *Journal of Social Work Education* 44, no. sup3 (2008): 105-113.
- ^{xiv} Pinquart, Martin, and Silvia Sörensen. "Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 58, no. 2 (2003): P112-P128.
- ^{xv} Schulz, Richard, and Lynn M. Martire. "Family caregiving of persons with dementia: prevalence, health effects, and support strategies." *The American journal of geriatric psychiatry* 12, no. 3 (2004): 240-249.
- ^{xvi} Metzelthin, Silke F., Ellen Verbakel, Marja Y. Veenstra, Job Van Exel, Antonius W. Ambergen, and Gertrudis IJM Kempen. "Positive and negative outcomes of informal caregiving at home and in institutionalised long-term care: a cross-sectional study." *BMC geriatrics* 17, no. 1 (2017): 232.
- ^{xvii} Goetze, Heide, Elmar Braehler, Lutz Gansera, Astrid Schnabel, and Norbert Koehler. "Exhaustion and overload of family caregivers of palliative cancer patients." *Psychotherapie, Psychosomatik, Medizinische Psychologie* 65, no. 2 (2015): 66-72.
- ^{xviii} Takai, Michiko, Megumi Takahashi, Yumi Iwamitsu, Satoru Oishi, and Hitoshi Miyaoka. "Subjective experiences of family caregivers of patients with dementia as predictive factors of quality of life." *Psychogeriatrics* 11, no. 2 (2011): 98-104.
- ^{xix} Roth, David L., Martinique Perkins, Virginia G. Wadley, Ella M. Temple, and William E. Haley. "Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults." *Quality of life research* 18, no. 6 (2009): 679-688.
- ^{xx} Wigglesworth, Aileen, Laura Mosqueda, Ruth Mulnard, Solomon Liao, Lisa Gibbs, and William Fitzgerald. "Screening for abuse and neglect of people with dementia." *Journal of the American Geriatrics Society* 58, no. 3 (2010): 493-500.
- ^{xxi} Yan, Elsie. "Abuse of older persons with dementia by family caregivers: results of a 6-month prospective study in Hong Kong." *International Journal of Geriatric Psychiatry* 29, no. 10 (2014): 1018-1027.
- ^{xxii} Litzelman, Kristin, Erin E. Kent, Michelle Mollica, and Julia H. Rowland. "How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways." *Journal of Clinical Oncology* 34, no. 29 (2016): 3554.
- ^{xxiii} Gouin, Jean-Philippe, Ronald Glaser, William B. Malarkey, David Beversdorf, and Janice Kiecolt-Glaser. "Chronic stress, daily stressors, and circulating inflammatory markers." *Health Psychology* 31, no. 2 (2012): 264.
- ^{xxiv} Kiecolt-Glaser, Janice K., Kristopher J. Preacher, Robert C. MacCallum, Cathie Atkinson, William B. Malarkey, and Ronald Glaser. "Chronic stress and age-related increases in the proinflammatory cytokine IL-6." *Proceedings of the national Academy of Sciences* 100, no. 15 (2003): 9090-9095.
- ^{xxv} Von Känel, Roland, Joel E. Dimsdale, Paul J. Mills, Sonia Ancoli-Israel, Thomas L. Patterson, Brent T. Mausbach, and Igor Grant. "Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer." *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 61, no. 9 (2006): 963-969.
- ^{xxvi} Gouin, Jean-Philippe, Liisa Hantsoo, and Janice K. Kiecolt-Glaser. "Immune dysregulation and chronic stress among older adults: a review." *Neuroimmunomodulation* 15, no. 4-6 (2008): 251-259.
- ^{xxvii} Epel, Elissa S., Elizabeth H. Blackburn, Jue Lin, Firdaus S. Dhabhar, Nancy E. Adler, Jason D. Morrow, and Richard M. Cawthon. "Accelerated telomere shortening in response to life stress." *Proceedings of the National Academy of Sciences* 101, no. 49 (2004): 17312-17315.
- ^{xxviii} Schulz, Richard, and Paula R. Sherwood. "Physical and mental health effects of family caregiving." *Journal of Social Work Education* 44, no. sup3 (2008): 105-113.
- ^{xxix} Brown, Stephanie L., Randolph M. Nesse, Amiram D. Vinokur, and Dylan M. Smith. "Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality." *Psychological science* 14, no. 4 (2003): 320-327.
- ^{xxx} Spillman, Brenda C., Jennifer Wolff, Vicki A. Freedman, and Judith D. Kasper. "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving," April 1, 2014.
<https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-study-caregiving>.

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- xxxvi Brown, Stephanie L., Dylan M. Smith, Richard Schulz, Mohammed U. Kabeto, Peter A. Ubel, Michael Poulin, Jaehee Yi, Catherine Kim, and Kenneth M. Langa. "Caregiving behavior is associated with decreased mortality risk." *Psychological science* 20, no. 4 (2009): 488-494.
- xxxvii Fredman, Lisa, Jane A. Cauley, Marc Hochberg, Kristine E. Ensrud, Gheorghe Doros, and Study of Osteoporotic Fractures. "Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures." *Journal of the American Geriatrics Society* 58, no. 5 (2010): 937-943.
- xxxviii Roth, David L., William E. Haley, Martha Hovater, Martinique Perkins, Virginia G. Wadley, and Suzanne Judd. "Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis." *American journal of epidemiology* 178, no. 10 (2013): 1571-1578.
- xxxix O'Reilly, Dermot, Sheelah Connolly, Michael Rosato, and Chris Patterson. "Is caring associated with an increased risk of mortality? A longitudinal study." *Social science & medicine* 67, no. 8 (2008): 1282-1290.
- xl Ramsay, Susan, Emily Grundy, and Dermot O'Reilly. "The relationship between informal caregiving and mortality: an analysis using the ONS Longitudinal Study of England and Wales." *J Epidemiol Community Health* 67, no. 8 (2013): 655-660.
- xli National Research Council. "Informal caregivers in the United States: prevalence, caregiver characteristics, and ability to provide care." In *The role of human factors in home health care: Workshop summary*. National Academies Press (US), 2010.
- xlii Hendrix, Cristina C., and Charlene Ray. "Informal caregiver training on home care and cancer symptom management prior to hospital discharge: a feasibility study." In *Oncology nursing forum*, vol. 33, no. 4. 2006.
- xliiii Belle, Steven H., Louis Burgio, Robert Burns, David Coon, Sara J. Czaja, Dolores Gallagher-Thompson, Laura N. Gitlin et al. "Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial." *Annals of internal medicine* 145, no. 10 (2006): 727-738.
- xliv Gitlin, Laura N., Laraine Winter, Tracey Vause Earland, E. Adel Herge, Nancy L. Chernett, Catherine V. Piersol, and Janice P. Burke. "The Tailored Activity Program to reduce behavioral symptoms in individuals with dementia: feasibility, acceptability, and replication potential." *The Gerontologist* 49, no. 3 (2009): 428-439.
- lv Mittelman, Mary S., David L. Roth, Olivio J. Clay, and William E. Haley. "Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention." *The American Journal of Geriatric Psychiatry* 15, no. 9 (2007): 780-789.
- lvi Gitlin, Laura N., Laraine Winter, Mary Corcoran, Marie P. Dennis, Sandy Schinfeld, and Walter W. Hauck. "Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative." *The Gerontologist* 43, no. 4 (2003): 532-546.
- lvii Hendrix, Cristina C., Richard Landerman, and Amy P. Abernethy. "Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers." *Western journal of nursing research* 35, no. 5 (2013): 590-610.
- lviii Patel, Anita, Martin Knapp, Andrew Evans, Inigo Perez, and Lalit Kalra. "Training care givers of stroke patients: economic evaluation." *Bmj* 328, no. 7448 (2004): 1102.