

## Family Caregiving for Older Adults: How does caregiving affect the caregivers' health?

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### Demographic and Epidemiologic Transitions Will Result in Increasing Older Adults with More Care Needs

The world's population is growing and aging. The percent of the world's population who are aged 65+ has been rising slowly and is about to spike in growth. In the United States, the first wave of "Baby Boomers" is beginning to reach retirement age. Between 2000 and 2010, the percent of the population aged 65+ grew from 12.3% to 13%; by 2020, this is projected to grow to 16.1%.<sup>1</sup> These trends are even more pronounced in less developed settings where, historically, life expectancy and the old age population have been small. For example, in Mexico, the proportion of the population who are aged 65+ is projected to almost quadruple between 2000 and 2050, from only 5.2% to 22.1%. Less developed regions will be home to 78% of the world's aged in by 2050.

Added life expectancy is not healthy life expectancy, but instead reflects an expansion of morbidity.<sup>2</sup> Disability is common in old age and causes much of older adults' physical care needs. In the U.S., roughly half of adults aged 65+ have a disability (46% men, 55% women).<sup>3</sup> Globally, 46% of adults aged 60+ have a moderate or severe disability; lower and middle-income countries have a higher prevalence of disability (e.g., South-East Asia, 59%) than higher income countries (36.8%).<sup>4</sup> The growing burden of non-communicable diseases also means that future generations will be aging with multi-morbidity and potentially poly-pharmacy that require relatively skilled, para-medical care.<sup>5</sup> Many older adults lack financial resources to provide for their health care, as they generally lack access to pension and other benefits that are common support structures in developed settings.<sup>6</sup> Health care access is a further challenge

for the elderly in developing settings, exacerbated because older people tend to live in rural areas where health facilities, in particular facilities specializing in geriatrics, are scarce.<sup>7-10</sup>

In lower- and middle-income countries, the care needs of older persons nearly always fall to family members alone.<sup>11,12</sup> In many areas of the world, there is a cultural expectation that older people will live with and receive their care from relatives than in developed settings.<sup>13,14</sup> In India, over 70% of the older population lives with family members.<sup>6</sup> Though this is culturally normative, developing and middle-income settings also commonly lack formal care infrastructure, such as long-term or residential care facilities,<sup>8</sup> to support older adults if they have more substantial needs than what the family can provide. Even in the U.S. that has long relied on nursing homes and an extensive cadre of formal long-term care and supportive services, many family members still provide informal caregiving: roughly 20% of US adults are caring for another adult,<sup>15</sup> and of those who are aged 65+, 25% are caring for a spouse.

### Gaps Remain in What We Know about the Health Effects of Caregiving in the US

Caregiving has important implications for the health, social and economic well-being of the caregiver. Namely, providing care can be physically, emotionally and financially taxing. A fairly robust research literature on US caregivers and their physical and mental health dates back at least 40 years and generally has shown caregiving is associated with lower mental and physical health.<sup>16-23</sup> In addition, there is some etiologic research that suggest that Alzheimer's caregivers have lower cardiovascular reactivity and physiological dysfunction compared to non-caregivers.<sup>22-28</sup>

The dominant theoretical paradigms in caregiving research are generally from the behavioral and social sciences (e.g., ecological

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framework,<sup>29</sup> life course theory,<sup>30</sup> stress process model<sup>31,32</sup>, which richly articulate many of the social processes at play in individuals caring for a family member. On the other hand, biomedical research, including epidemiologic investigations, are largely atheoretical,<sup>33-35</sup> at least explicitly so. Those biomedical models that do include physiological changes and include morbidity and mortality<sup>36, 37</sup> have recently been called into question. Specifically, the notion of a linear physiological process from caregiving to morbidity to mortality does not bear weight in light of competing evidence while that caregiving may be associated with increased morbidity;<sup>18-20</sup> US caregivers consistently show lower mortality.<sup>38-41</sup> Thus, caregiving research sorely lacks a coherent and testable theory that integrates biomedical and psychosocial studies of caregiving.

Moreover, there are still critical gaps in the understanding of the causal inference of the association between caregiving and the caregiver's subsequent health outcomes. Simply put, we are still not confident whether and how caregiving affects the caregivers' physical health? Like other social phenomenon, caregiving cannot be randomly assigned ethically; thus, randomized controlled trials, otherwise the gold standard for developing causal evidence, are essentially not available for caregiving research. Instead, the research relies on quasi-experimental methods and increasingly rigorous statistical approaches for leveraging causal estimates from observational data. However, much of this literature invokes study designs and analytic methods with limited ability to inform whether caregiving *causes* changes in health.<sup>42</sup> Some of these limitations are due to inherent difficulties of studying caregiving, such as the practical challenges of identifying caregivers before they are caregivers, finding adequate and appropriate comparison groups, and an heavy reliance on cross-sectional designs and clinic-based samples.<sup>16, 43</sup>

### **There Are Effective Caregiving Interventions from the U.S., But Will They Work in India?**

Although it still remains somewhat unclear whether and how caregiving materializes in long-term effects on the caregivers' health, there is some more evidence about the effectiveness of existing interventions to reduce mental health and subjective health outcomes for the caregivers. Most of these interventions are segmented by disease type (i.e., stroke caregivers, Alzheimer's caregivers, cancer caregivers); however, they generally address the core idea of reducing caregiving stress. The Rosalynn Carter Institute for Caregiving offers a

particularly useful database of caregiving interventions across these typical disease groupings.<sup>44</sup> One robustly evaluated program is the New York University (NYU) Caregiver Counseling and Support Intervention, a combination individual and family based counseling intervention for caregivers and their families. This intervention has been shown to reduce depressive symptoms in the caregivers and even delay nursing home placements.<sup>45-49</sup> Other interventions tend to focus on developing practical caregiving skills to improve mastery and self-efficacy and psychosocial approaches to reducing burden.

There may well be much to learn from the U.S., European and other high income countries' experiences and solutions for caregiving to their own aging populations. However, some questions about how caregiving affects the caregivers' health that remain unresolved. These questions put important cracks into the foundation of this work on caregiving interventions from the Global North vis-à-vis its applicability to the Global South. For instance, one-on-one interventions which treat caregiving as a health behavior remain the norm. Despite strong social norms determining who becomes a caregiver, caregiving in the Indian context operates as more of a family than an individual process. Thus, interventions from the Global North may be reductive – simplifying complex family decision making and dynamics into individual level phenomena and thereby diminishing the intervention's validity or effectiveness. Moreover, social norms about transportation, the expected housework that keep women in the home during the day, and even what topics are appropriate to share outside the family may render group-based interventions impractical or even culturally inappropriate. Lastly, many interventions focus on linking with existing formal health care services; these interventions make sense in the context of places with strong formal services and health insurance, but perhaps may not in India where health care is highly decentralized and largely paid for out of pocket.

Instead, India may face unique and valuable opportunities to “leapfrog” over existing models from the US and Global North. Rather than adapt existing interventions of one-on-one or group based in-person interventions, great opportunities exist to leverage new technologies – mobile phones, tablets/smartphones, Health/telemedicine – to benefit caregivers. Creative problem-solving may yield powerful and beneficial resources that make sense for the Indian context as well as to help caregivers, keep them healthy, and able to provide this crucial care to older adults.

## Building a Foundation of Caregiving Research in/for/by Low and Middle-Income Countries: What do We Need to Know?

The caregiving research base from lower and middle-income countries still largely remains in its infancy. In order to build crucial evidence about aging, families and caregiving, additional effort and resources are necessarily to address basic, etiologic questions in order to prioritize and target interventions most effectively. Despite the strong, genuine desire to move directly into intervention research, these more foundational questions—who are the caregivers, are they stressed, and what kinds of help do they want/need – must first be addressed through an investment in observational biomedical and social science research. Interdisciplinary research offers vital insights into both the social, behavioral and pathophysiological processes at play for caregivers and their health and cannot be undervalued. Moreover, establishing better evidence of these central questions must precede extensive intervention solutions in order to prioritize and make best use of the resources spent on interventions.

Ongoing work about caregiving and aging needs better documentation and evidence. Many programs go unnoticed because they lack studies showing their data and effectiveness published in peer-reviewed journals. Rather than reinvent the wheel, we could replicate existing models after they have been proven effective. However, as a discipline of gerontology and geriatrics, we must do more and better work to document what we have done and have seen improve people's lives. Data and evidence provide the best guides, and we should put them at the center of our future efforts to address the needs of caregivers and their health.

### KEY TAKE HOME MESSAGES

1. There is evidence from the Global North that caregiving affects the caregivers' health, however the precise mechanisms by which caregiving affects caregivers' health remain somewhat elusive
2. Although interventions have been proven effective for minimizing depression and subjective measures of health they: a. are not well established to have long-range effects on the caregivers' health and b. may not be appropriate for the Indian context
3. More foundational work – etiologic research to prioritize interventions and formative work to pilot intervention efforts – is necessary in India and other low/middle-income countries to develop culturally appropriate, cost-effective and evidence-based interventions to support caregivers and their health.

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