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## Ethical and Policy Implications of Financial Burden in Family Caregivers

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### Abstract

Palliative care nurses are key members of the health care team and provide support to patients and their families navigating chronic and life-limiting illness. Financial burden is an issue inherent to chronic illness, yet has not been fully addressed in family caregivers. The purpose of this paper is to 1) provide a case study of a family caregiver navigating chronic illness with her daughter and the associated financial and employment consequences; and 2) review the nursing ethical, policy, and practice implications of financial burden for family caregivers. The ethical implications of financial burden in family caregivers relate to health equity and health outcomes for both the patient and family caregiver in treatment access and quality. The policy implications include state and federal policies related to caregiver compensation and support and family medical leave. Palliative care nurses play an integral role in addressing caregiver financial burden through assessment, education, referral, and policy support. Family caregivers are essential to the palliative care team, and palliative care nurses have the opportunity to lead initiatives to support the financial well-being of family caregivers in practice, research, and policy settings.

### Keywords

palliative care; family caregiving; financial well-being; health policy; health care ethics; health equity

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Palliative care nurses are key members of the health care team who facilitate care for both patients with chronic and life-limiting illness and their family caregivers.<sup>1</sup> Fundamental to the chronic illness experience is the high cost of health care. In 2017, one in seven individuals reported being part of a family that was struggling to pay medical bills.<sup>2</sup> There

is growing recognition of financial burden or toxicity in individuals with chronic illnesses, but the financial impact of chronic illness and caregiving on family caregivers has not been fully explored. Throughout this paper we will describe financial burden, toxicity, and well-being as related issues. Financial burden or toxicity is defined as the adverse effects of financial strain caused by chronic illnesses on the well-being of patients, families, and larger society.<sup>3</sup> Tucker-Seeley and colleagues propose that financial well-being, the sense of financial security and financial choices, is an interaction among material, behavioral, and psychosocial domains.<sup>4</sup> The purpose of this paper is to use a case example of financial burden in family caregiving from one of the authors to explore sources of financial burden, ethical and policy implications, and opportunities for palliative care nurses to address the financial burden experienced by family caregivers.

## Case Example

MTH became a family caregiver when she was 27 and just beginning her career as a nurse practitioner. Her one-year-old daughter was diagnosed with epilepsy with severe, recurrent seizure clusters resulting in multiple hospitalizations throughout cold and flu season. In addition to MTH's job as a nurse practitioner, she was in school working on my doctorate of nursing practice (DNP). She also had an older child and was pregnant with her third. Due to her part-time job status and length of employment, she was eligible for family and medical leave (FMLA), but not paid leave. Her husband, also in graduate school, received a monthly stipend that was enough for one person to live on, not four or almost five. Luckily, MTH was also working as a graduate research assistant with an associated monthly stipend, which added some buffer to their financial situation, with \$3,000 (USD) per month net income rather than \$1500. For 12 weeks, while on FMLA, she spent time at home, grappling with her daughter's new diagnosis that required medication (often \$100 per month or more out of pocket), testing with EEGs and MRIs, and visits with specialists. MTH was grateful for the time without one of her jobs, so she could focus on her daughter, but the loss of income was significant for her family.

Due to her daughter's health, over the next four years, MTH rotated in and out of the workforce as a nurse practitioner. In that field and at that time, flexibility was not part of the equation. MTH understood *why* (the dynamics of scheduling and patient access), but that did not omit the financial and career challenges for her family and her in both the short- and long-term. She eventually graduated with her DNP degree and sought employment in academia, anticipating its possibility for greater work flexibility. MTH needed to continue to develop her career, support her family, and carry out her caregiving responsibilities. Not all academic jobs are created equal, and it quickly became apparent, for many reasons, that she would not have the flexibility she needed for her family situation. Though MTH asked for a reallocation of duties that would better align with her family's needs, very few accommodations were made. After one of her daughter's seizure clusters, MTH decided to request paid family leave through her employment benefits. She needed documentation from her daughter's physician to support this request. The physician wrote for MTH to have ½ day off every month. Due to the limitations of ½ day off per month and the actuality of support that her daughter needed, MTH did not further pursue this path.

After three years, MTH left this job, and a \$96,000 annual income, to piece together income through adjunct faculty positions as well as teaching and research assistantships in her PhD program. Unfortunately, her income rarely exceeded \$30,000 per year. All of these positions were remote and asynchronous, which allowed MTH to fit her work schedule around her family's needs. During that same year, MTH's daughter went into status epilepticus and respiratory arrest—she was placed on a ventilator for five days while they heavily medicated her to break the seizure cycle. MTH was grateful for her flexible schedule, yet she was making one-third of the income she could have been making as a full-time faculty member. The medical and incidental costs (travel costs, food, and child care) were financially overwhelming. Now, three years out, MTH and her family are barely recovering from these financial challenges.

MTH now has a new academic job, and during the interview process she was very clear with prospective employers that she would not be a good fit for their organization if flexibility for her caregiving situation was not honored. She is lucky and grateful to have her job, but she also acknowledges the ten-year process and two advanced degrees (DNP and PhD) that supported her path here. For some caregivers, especially essential workers, there is little-to-no flexibility or hope of flexibility for leave, let alone paid leave. This situation places those who are most essential to the functioning of society in a position of choosing between earning a living wage and their caregiving responsibilities.

## Employment, Insurance, and Financial Burden

MTH's story of family caregiving, employment, and financial burden is common for many families. The privilege of education, coming from a middle-class background, being knowledgeable of the healthcare system and being White buffered the financial challenges MTH experienced. Knowing how difficult it was for her, even with her privilege, the authors recognize that other family caregivers are navigating even greater financial obstacles with fewer resources. There are approximately 53 million caregivers in the U.S who provide care for either their family members, friends, or neighbors with chronic illnesses.<sup>5</sup> Among family caregivers, over half are employed either full-time or part-time, with sixty-nine percent working at least 35 hours per week.<sup>6</sup> Caregivers, regardless of age, report challenges balancing work and caregiving duties. Specifically, more than half of them report coming in late, leaving early, or taking time off to fulfill their caregiving role.<sup>7</sup>

Forced to make sacrifices, some caregivers leave the workforce altogether. Family caregivers who either disrupt their careers or leave the work force completely to fulfill their caregiving role can experience substantial economic risk and both short- and long-term financial strains.<sup>8</sup> Over 75% of individuals who retired early to care for their loved ones would have prolonged their engagement in the workforce if they had access to alternative work arrangements such as flexible hours/shifts, telecommuting, compressed schedules, paid leave, or phased retirement.<sup>7</sup> The total opportunity cost of forgone earnings among caregivers is approximately \$67 billion and mainly due to the lower likelihood of engaging in the workforce.<sup>8</sup> Including the projected changes in work participation, hours worked, and real wages, the opportunity costs in 2050 will increase up to \$139–\$147 billion.<sup>8</sup> However, if family caregivers aged 50 and above have increased access to accommodations in the

workplace, U.S Gross Domestic Product (GDP) could increase by an additional \$1.7 trillion (5.5 percent) in 2030 and by \$4.1 trillion (6.6 percent) in 2050.<sup>7</sup>

One of many workplace challenges in the United States is the linkage of health insurance and other important benefits with employment. In response, the Affordable Care Act and the Healthcare Marketplace were created, but paying for private health insurance can still be costly for individuals, averaging \$456 per month for individuals and \$1,152 per month for families in 2020.<sup>9</sup> For family caregivers who have to leave their employment and do not qualify for government subsidies, Medicaid, or Medicare, this can be financially overwhelming. Additionally, immigrants and other historically minoritized groups are impacted by decreased access to health insurance.<sup>10,11</sup> In this case example, MTH was fortunate enough to have access to insurance through her husband's employment or student health plans. Yet, even that coverage did not totally relieve the burden of their out-of-pocket costs for health care. During their years as students, when they were considered low income, they applied for the hospital's charitable care support to help manage hospital bills, some exceeding \$2,000 per hospital stay. Most caregivers, whether or not they co-reside with the care recipient, contribute financially to their caregiving situation.<sup>5</sup> The estimated economic value of family caregivers' unpaid contributions to the care of those with chronic illness is approximately \$470 billion.<sup>11</sup> Out-of-pocket costs are a substantial contributor to the financial burden of family caregivers, costing about \$7,000 per year on average.<sup>11-12</sup> Historically minoritized groups, such as Latino caregivers, contribute more financially to caregiving than their White counterparts, while navigating more challenges with access to health insurance.<sup>5,11-12</sup>

### **Indirect/Incidental Financial Costs of Caregiving**

Often, the incidental costs related to chronic illnesses are ignored. These costs can include travel to receive health care, housing and basic necessities, increased food costs due to decreased time and need for convenience, and child or adult care services. Long-distance caregivers have the highest average annual expenses due to caregiving.<sup>6</sup> For some caregivers, these costs may mean dipping into savings or retirement, taking on debt, or foregoing treatment of their own health problems.<sup>6</sup> Every year, for the past ten years, MTH and her spouse not only exceeded their maximum out-of-pocket deductible, but also incurred incidental costs including travel to specialists ranging from one to five hours in travel time, the expense of a ketogenic diet, and non-coverable costs for specialized child care and therapies to meet their daughter's needs. There are also secondary family impacts related to chronic illness, including the additional support they provide their other children as they navigate family illness. These other expenses include counseling services, childcare, and "feel good" costs with gifts, activities, and time that help them know they are still seen and loved in their family.

### **Caregiver Personal Health and Financial Impact**

The health of family caregivers is another area of unacknowledged financial stress. MTH's health has declined over the past ten years with two autoimmune diseases and severe food allergies. Whether she was destined to experience these issues regardless of her caregiving

role, it is difficult to say. We do know that family caregivers experience negative health impacts along with social, emotional, and financial impacts.<sup>5, 13</sup> Poor health adds even more pressure to caregiver finances, including specialty health care costs, prescription medications, and impacts on employment. MTH now sees two specialists, takes multiple medications for chronic illness management, and too, follows a specialized diet. While she is able to maintain full-time employment, that is only possible because of the flexibility she has found in her current job, a job she qualified for due to her advanced education (DNP and PhD). Reflecting on MTH's experiences, it is important to consider what other caregivers do without job flexibility for their own poor health.

While caregivers often report growth and satisfaction with their caregiving role, there are well-documented physical and mental health consequences of caregiving including increased anxiety and depression, higher rates of chronic illnesses, and even greater mortality risk.<sup>5,13–16</sup> There is an increase in the percentage of family caregivers reporting declines in their self-rated health from 17 percent in 2015 to 21 percent in 2020.<sup>5</sup> This is especially true among younger caregivers (aged 18 to 49) who are more likely to report having fair or poor health due to their caregiving duties.<sup>5</sup> Among family caregivers aged 50 and above, 65% report high levels of emotional and physical strain due to their caregiving role.<sup>5</sup> Data are limited that directly address the economic toll for these chronic health issues in family caregivers, which compounds the financial strain they have from caregiving. That the cost of chronic illness annually in the United States is 1.1 trillion dollars for direct health care costs and 3.7 trillion dollars when indirect health care costs are included.<sup>17</sup> In addition, the social determinants of health, such as gender identity, sexual orientation, race/ethnicity, socioeconomic status, and education levels impact health and illness, with those who have been historically marginalized experiencing these effects most acutely.<sup>10</sup> For individuals, direct health care costs average \$6,032 annually; five times that of an individual without a chronic illness.<sup>18</sup>

## Ethical Implications of Financial Burden in Caregivers

There are broad ethical principles that support health care practice including beneficence (promoting good for others), nonmaleficence (do no harm), autonomy (self-determination), and justice (equitable distribution of resources).<sup>19</sup> Along with these broad principles, the American Nurses Association has outlined the Nursing Code of Ethics that includes provisions for the promotion of human dignity, the commitment of nurses to the patient (whether the patient is an individual, family, or community), advocacy for the rights, safety, and health of patients, collaboration with other health professionals to reduce health disparities, and integration of social justice into nursing and health policy.<sup>20</sup> These ethical principles directly apply to the financial burden and needs of family caregivers including promoting the well-being of the care recipient and caregiver (facilitating access to care and resources for both parties), preventing harm related to financial burden (e.g. forgone care for caregiver or care recipient or decreased access to treatments),<sup>10</sup> providing resources and support that expand treatment options and facilitate patient and caregiver decision-making, and support of those patients and caregivers that are most at risk for financial challenges due to social determinants of health.<sup>10,21–22</sup> Ethical issues of access, equitable treatment and outcomes, and holistic health and well-being<sup>21,23</sup> impact caregivers *and* patients

experiencing financial toxicity over the course of chronic disease. Screening for insurance, access to financial support through local, state, and federal resources, employment and employment needs, and financial well-being all need to be integrated into chronic disease management for ethical care of both the care recipient and caregiver.<sup>21</sup>

MTH, from the case example, experienced positive and negative examples of support for her family's financial needs. Some positive examples include: the pharmacist who printed off a coupon and applied it to her daughter's prescription without being asked; the nurse who went out of her way to coordinate imaging and evaluations for the same week to limit their travel and MTH's time away from work; the doctors who gave their personal numbers to call to keep MTH's daughter out of the hospital; the pediatrician who wrote the letter that facilitated MTH's unpaid leave which allowed her to keep her job; the nurse practitioner and dietitian who coordinated free school lunches that aligned with the ketogenic diet for their daughter; and finally, the man in the billing office who made them aware of charity care when they could not afford the out-of-pocket costs for their daughter's multiple hospitalizations. Such actions align with ethical principles of beneficence, nonmaleficence, justice, and autonomy.<sup>19</sup> These actions also demonstrate the impact of health care professionals who work within and beyond the scope of their job description to make a difference for the financial well-being of family caregivers.<sup>21</sup>

## Policy Implications of Financial Burden in Family Caregivers

For family caregivers, there are numerous policy implications related to financial burden: 1) financial burden and its relationship to employment; 2) direct health care costs for the care recipient and caregivers; 3) incidental costs related to the context of caregiving; and 4) the impacts of the social determinants of health on caregiving (See Table 1). There has been movement at both the federal and state level to support the complex needs, including financial well-being, of family caregivers.

### Federal Policies in the United States

- Family and Medical Leave** The Family and Medical Leave Act of 1993 (FMLA) ensures up to 12 work weeks of unpaid leave per calendar year to eligible employees for approved family and medical leave reasons and, adherent to amendments to the law, up to 26 work weeks of leave in a single 12-month period to care for a seriously ill or injured covered service member.<sup>24</sup> Approximately 60 percent of employees across the United States qualify for FMLA, given its provisions. Only family caregivers to newborn children and seriously ill family members are eligible under the federal law's coverage.<sup>24</sup> FMLA coverage often neglects a significant segment of family caregivers, particularly working women and historically minoritized workers. These populations are more likely to work in jobs that do not require FMLA protections.<sup>24</sup> Employees with minimum wage salaries are less likely to benefit from FMLA. Individuals who are African American, Latino/a and minimum wage employees are among the most vulnerable population dealing with the employers' non-compliance with FMLA.<sup>24</sup> Only 10 states have broadened

FMLA coverage by covering other family members, prolonging the length of leave, or covering smaller employers. Among the 10 states, the District of Columbia has provided the most comprehensive FMLA coverage.<sup>7</sup> There are organizations, including PL+US that are advocating for robust paid family leave in the United States.<sup>25</sup> The Build Back Better Act, which passed in the United States House of Representatives in 2021, included comprehensive paid family leave. The fate of this bill continues to be unclear, including the provisions for paid family leave.<sup>26</sup>

- **Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act** The enactment of the RAISE Family Caregivers Act has paved the way to enhance access to available caregiver resources, and integrate family caregivers as a member of the interdisciplinary team.<sup>27</sup>
- **The American Rescue Plan Act** The American Rescue Plan Act was signed by President Biden on March 11, 2021 during the COVID-19 pandemic, supporting family caregivers in various ways. This Act increased the federal Medicaid funding to states by up to 10 percentage points to provide home- and community-based services (HCBS).<sup>27</sup> Through the American Rescue Plan, more financial aid is given to family caregivers with children by extending the child tax credit, as well as the \$1,400 relief checks, and paid leave for federal workers, lessening the financial burden of caregiving. The federal Dependent Care Tax Credit (DCTC) is designated for employees who pay another individual to care for their child or another dependent.<sup>24</sup>
- **National Family Caregiver Support Program** Another example of federal policy for caregivers is the National Family Caregiver Support Program (NFCSP) founded in 2000 under Title II-E of the Older American Act (OAA).<sup>24</sup> This policy provides funding for individuals aged 18 and older to fulfill a caregiving role for a family member who is either 60 years and older, or has Alzheimer's disease and other cognitive impairments. Furthermore, 10 percent of state funding can be reserved to support grandparents or other relatives (aged 55 and older) caring for a child under 18 years old or an adult with disabilities.<sup>24</sup>
- **Lifespan Respite Care Act of 2006** The Lifespan Respite Care Act of 2006 was created for family caregivers of individuals with special needs to enhance their access to community-based respite care services. Medicaid home and community-based service (HCBS) waivers in which a "self-" or "participant-directed" component can enable the waiver recipient to choose and pay their own caregivers, including family caregivers.<sup>24</sup>

### State Policies in the United States

In addition to federal policies, state and local laws have established increased support for family caregivers.<sup>11</sup>

- **Caregiver Advise, Record, Enable (CARE) Act** Fifty-three states and territories across the United States have enacted the CARE Act mandating identification of family caregivers during hospitalization and notification of

discharge and discharge instructions when individuals transition back to the community.<sup>24</sup>

- **Financial Support for Caregivers** Some of the most effective initiatives offering financial support to family caregivers include Hawaii's Kupuna Caregivers Assistance Act, which provides a weekly voucher to cover the hiring cost of long-term care services for their older loved ones.<sup>7</sup> Also, Washington's Long-Term Care Trust Act, assists eligible family caregivers with the expenses of long-term care.<sup>7</sup>
- **Caregiver Workplace Discrimination** While some regions across the country have enacted laws that protect family caregivers from discrimination at their workplaces (e.g., localities across 21 states have provisions emphasizing family responsibility), there are only two states (Delaware and the District of Columbia) that specifically address family caregivers as a protected category under state law.<sup>7</sup>

## Role of Palliative Care Nurses

Palliative care nurses are in a unique position to address financial burden and well-being in family caregivers through clinical and policy-based actions.<sup>1</sup> Palliative care nurses are often the first point of contact and coordinate referrals for patients and caregivers to other members of the health care team. Palliative care nurses also provide assessment and screening for symptoms and education about symptom management, treatment plans, medications, and follow-up care. They may be the key coordinator and resource for caregivers and patients.<sup>1</sup> They may work with other health professionals, such as social workers, to facilitate resource access. Therefore, it is an ethical responsibility for financial burden and well-being to be addressed by palliative care nurses, and for organizations to provide the needed support to make this possible for nurses who are carrying multiple responsibilities. Though the perspective of this paper is focused on palliative care nursing and care for patients with chronic and life-limiting illnesses and their family caregivers, the principles are applicable to the wider nursing profession.

Possible nursing interventions to address financial burden in family caregivers include: financial toxicity screening; education about community resources to support employment, FMLA or other paid leave benefits, insurance access, medication assistance programs, and organizational charity care options; referral coordination to social work and financial advisors for additional resource support; empowerment of family caregivers through discussion of resources and creative approaches to meeting financial obligations through resource utilization; and advocacy at the organizational, community, state, and federal level for policies that support paid family leave for family caregivers, employment protection for family caregivers, health insurance and treatment access, and services and supports for family caregivers.<sup>21</sup>

These measures recommended by Helping States Support Families Caring for an Aging America are an excellent guide for nursing policy advocacy.<sup>28</sup>



1. Empower family caregivers with increased access to available resources, including respite care, FMLA coverage, flexible work schedule, and formal trainings provided for family caregivers;
2. Develop comprehensive and robust databases that will expand existing caregiver support programs or inform new policies to support family caregivers;
3. Establish cross-sector partnerships (such as collaboration among Departments of Aging, housing, transportation, schools, and health plans) to meet family caregivers' needs; and
4. Bolster aging initiatives and family caregiving programs through formal channels to prioritize family caregiving.<sup>28</sup>

The authors are examining financial interventions that have been tested in family caregivers to understand a path forward for health care delivery and health policy change. It is anticipated that palliative care nurses will play a key role in these interventions. The authors' goal is to identify financial interventions and organizational/governmental policies that promote health equity and reduce disparities for historically minoritized populations who bear the greatest economic consequences related to caregiving.

## Conclusion

Family caregivers are being impacted financially, yet they continue to contribute to the economic and social well-being of our country. As Rosalynn Carter stated: "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."<sup>29</sup> Like change, death, and taxes, caregiving and its economic impact is an inevitable and universal human experience that can be supported by palliative care nurses within clinical environments and community, state, and federal policy landscapes. Organizations are key to supporting nurses in advocating for and implementing interventions that address caregiver financial well-being. Family caregiving is a valuable economic and social resource in the United States that should not negatively impact the financial security and economic future of family caregivers.

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**Table 1:**

Summary of Policies for Family Caregivers and Financial Burden

Policy	Type of Support
Family and Medical Leave Act of 1993	Employment, direct health care costs with insurance, with expansion to robust paid family leave could also address the social determinants of health
Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act	Direct and incidental costs with resource access, potential for employment protection by providing more resources to caregivers who are employed, potential to address social determinants of health if fully deployed in under-resourced family caregiving communities
The American Rescue Plan Act	Potential to address employment, direct and incidental costs, and social determinants of health. Limited by timeframe with some benefits that expired in 2021 and some that are expiring in 2022
National Family Caregiver Support Program	Potential to address employment, direct and incidental costs, and social determinants of health. Limited by the populations that qualify for this program.
Lifespan Respite Care Act of 2006	Potential to address employment, direct and incidental costs, and social determinants of health. Limited by the populations that qualify for this program.
Caregiver Advise, Record, Enable (CARE) Act	Potential to address employment, direct and incidental costs, and social determinants of health if recognition of the caregiver also results in more referrals and supports for both the care recipient and caregiver.
Washington’s Long-Term Care Trust Act	Specifically supports direct health care costs for care recipient, but impact could go beyond with decreased caregiver burden (indirect and incidental caregiver costs), increased caregiver time (less employment conflict), and supporting under-resourced caregivers (social determinants of health)
Hawaii’s Kupuna Caregivers Assistance Act	Specifically supports direct health care costs for care recipient, but impact could go beyond with decreased caregiver burden (indirect and incidental caregiver costs), increased caregiver time (less employment conflict), and supporting under-resourced caregivers (social determinants of health)
Family Caregivers as Protected Category for Workplace Discrimination (Delaware and the District of Columbia)	Directly affects employment and financial burden, but has potential to impact other areas such as caregiver health and social determinants of health for under-resourced family caregivers.

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