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**Addressing Informal Caregiver Burnout in the United States:
Policies, Interventions, and Recommendations**

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Abstract

Informal caregiver burnout has been and will continue to be a significant public health concern in the United States, necessitating a comprehensive analysis of initiatives and policies to reduce its negative impacts. This paper provides an overview of existing approaches to address caregiver burnout at the individual, community, and national level, identifying critical gaps in policies and programs. By highlighting successful approaches in other developed countries, this paper presents comprehensive program and policy recommendations to strengthen informal caregiver support systems in the United States. Prioritizing these proposals can guide policymakers in creating a more supportive environment that values the crucial role of caregivers and improves their overall well-being. The paper concludes that to effectively address caregiver burnout, it is essential to implement integrated, wrap-around services tailored to the diverse needs of caregivers and ensure ongoing program evaluation. It emphasizes the need for the U.S. to re-evaluate its fiscal priorities related to public health by increasing caregiver support, especially given the growing elderly population and their increasing care needs.

Keywords: informal caregiver, caregiver burnout, Family Medical Leave Act (FMLA), paid family leave policies, caregiver support, caring for chronically ill, caregiver burden.

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Addressing Informal Caregiver Burnout in the United States: Policies, Interventions, and Recommendations

The population in America is aging rapidly, with the number of elderly people expected to nearly double in as little as 40 years (Pristavec & Luth, 2020). By 2030, it is estimated that there will be approximately 73 million older adults in the U.S., creating a greater need for informal caregivers to take care of the aging Baby Boomer generation (Pristavec & Luth, 2020). As the number of older adults increases, this demographic shift creates public health issues that need to be addressed. This includes an increased need and demand for programs and services to care for and support the elderly, especially as their health declines. The United States currently has limited paid family leave policies or programs in place to assist family members in caring for ill loved ones who require continuous care. In these instances, family members often have no choice but to take on the caregiving responsibilities themselves, as many are unable to afford the high cost of assisted living services and home health aides. Because of the exorbitant costs associated with hiring additional help to care for ill family members, informal caregiving continues to be the predominant form of home care in the U.S. (Oh et al., 2024).

The role of an informal caregiver is defined as either a family member or friend who provides unpaid and ongoing assistance to a person in need of long-term care (Tough et al., 2022). The goal of an informal caregiver is to help the dependent individual maintain a good quality of health and lifestyle (Gaspar et al., 2023). Informal caregiver responsibilities may include, but are not limited to, assisting with personal care through feeding and hygiene, aiding in mobility, managing household chores, assisting with medication administration, and overseeing health equipment monitoring, if applicable (Gaspar et al., 2023). When family members become informal caregivers, they face many challenges in their newfound role, which

is often unexpected. The challenges faced include physical demands, emotional strain, financial stress, isolation, and an overall reduced quality of life. All of these challenges can be extremely burdensome for the caregiver, oftentimes, leading to the condition of caregiver burnout (Gerain & Zeck, 2019). According to Maslach's theory, burnout is defined as a psychological syndrome with symptoms of emotional exhaustion, lack of personalization, and a diminished sense of accomplishment in daily tasks (Stodolska et al., 2023).

While being an informal caregiver places individuals at a higher risk of negative physical and mental health outcomes, implementing preventive measures and intervention programs can mitigate these negative health effects, thereby reducing burnout and stress levels among informal caregivers. This paper will examine existing policies and intervention programs related to preventing caregiver burnout at the individual, community, and national level. Recommendations will be provided on how to effectively provide integrated and wrap-around services that comprehensively address all facets of the caregiving experience, focusing on the support needs of targeted populations of caregivers to prevent burnout. Additionally, it will address gaps in U.S. policies supporting informal caregivers and propose policy recommendations, drawing comparisons with other industrialized nations best practices in this area.

Methods

This paper will analyze existing policies and intervention programs in the United States as far as their effectiveness in preventing caregiver burnout. I will then provide recommendations for change and improvements to existing U.S. programs and policies. My recommendations will include comparing U.S. policies to those in other countries that have successfully prevented caregiver burnout.

Research Strategy

I completed a review of academic articles describing the short- and long-term negative health outcomes and burnout rates of those in an informal caregiver role. I completed a thorough review of risk factors to identify what population/demographics of informal caregivers are most at risk of developing caregiver burnout. I conducted a systematic literature review to assess the needs of the population and identify benefits and gaps in services and programs aimed at preventing caregiver burnout, analyzing existing treatment programs, theories, and U.S. policies.

- a) Existing treatment programs and initiatives included Resources for Enhancing Alzheimer's Caregiver Health (REACH), Veteran Affairs (VA) Caregiver Support Program, Stress Management and Resiliency Training (SMART) , and the National Family Caregiver Support Program (NFCSP).
- b) Intervention theories to address informal caregiver burnout included cognitive behavioral therapy and the socioecological model. See Appendix A for the public health competencies addressed.
- c) Treatment needs assessment included the following: integration of primary care settings with interventions provided, psychosocial groups, online therapy/interventions, and respite services.
- d) Policies included reviewing existing U.S. national unpaid policies (specifically FMLA) and state paid policies.
- e) Successful interventions and/or policies to support informal caregivers/prevent burn-out in countries outside of the U.S. were included in the analysis to provide recommendations on changes in the U.S. programs and policies to address caregiver burnout, reduce gaps in

services, and provide a more integrated level of care for this population. See Appendix A for the public health competencies addressed.

- f) Data was gathered from the National Library of Medicine, The World Policy Center, American Association of Retired Persons (AARP), The Gerontologist Journal, The Journal of Aging and Health, The Bipartisan Policy Center, Health Services Research, BMC Public Health, Frontiers in Psychology, Journals of Gerontology, and Annals of Internal Medicine Journal.
- g) The data collected includes both primary data and secondary data.
- h) The data is generalizable to individuals (mostly adults) who are informal caregivers, regardless of the country they are in, as several of the articles are based in countries outside of the United States. Several of the studies focus on older adult caregivers, but the data is not limited to that population.

Target Population

All informal primary caregivers (family members or close friends) who provide care for elderly, chronically ill, and disabled individuals without receiving compensation. In particular, a focus was on creating support services for those caregivers who were higher at risk for developing negative health consequences and burnout.

Keywords

Key search terms: informal caregiver, caregiver burnout, caregiver burden, Family Medical Leave Act (FMLA), paid family leave, caregiver stress, caregiver anxiety, care for elderly, care for older adults, family leave policies, employee leave policies, medical leave policies, San Francisco paid leave, caregiver support, employee, caring for aging baby boomers, wellbeing, caregiver well-being, caregiver burden, caregiving for chronically ill, caregiver

intervention, support, caregiving for disabled, caregiving for elderly, FMLA shortfalls and/or gaps, support systems for caregivers.

Literature Review

Long-Term Care Need

As the population of older adults increases in the U.S. there has been a rise in the number of people needed individualized care. The aging population, increased lifespans, and rise in chronic health conditions have escalated the demand for both informal and formal caregivers in America (Beach et al., 2018). Approximately one out of every five adults in the U.S., totaling 53 million people, offers long-term care to aging, disabled, and chronically ill individuals (Utz, 2022). As life expectancy and rates of chronic disease are increasing in the world, there will be more older adults needing additional care and support as they age and greater demand on the American healthcare system to provide these programs and services (Gaspar et al., 2023).

Types of Care Options

The two types of care that exist for individuals who have long term care needs include formal care, defined as paid provided by a medical institution or someone trained to medically deliver care and informal care, which is the unpaid care of a sick person provided most often by a close family member or relative, or less often, by a neighbor or friend (Oh et al., 2024). Common types of formal care include home care assistants, assisted living homes, and nursing homes. Home care assistants help individuals with everyday tasks in their home environment and are usually paid at an hourly rate. Assisted living homes provide housing for older adults who require lower levels of assistance with activities of daily living (ADL). In contrast, nursing homes are for older adults who require very high levels of support with ADL. The cost for assisted living homes is high, and it is projected that by 2029, 54% of older adults will not be

able to afford them (Knickman & Snell, 2002). Among the 42% of older adults who require nursing home care, half spend two years or more there and shoulder the majority of these out-of-pocket costs (Knickman & Snell., 2002).

Increase in Demand for Informal Care and Who is Filling the Demand

Due to the high out-of-pocket costs for assisted living and nursing homes, and the fact that 36% of long-term care costs are covered by out-of-pocket expenses, many families in America are unable to afford these options and instead rely on family members to provide informal care for their loved ones (Knickman & Snell, 2002). The use of informal home care by older adults with disabilities saw a rise from 2004 to 2016, with informal home care being received by almost three-quarters of older adults with disabilities in 2016 (Oh et al., 2024). As the number of informal caregivers increases in the United States, this also increases their risk of experiencing caregiver burnout. The groups most likely to become informal caregivers include the following: women, middle-aged adults, the unemployed, domestic workers, adherents of religious faiths, and people with health conditions (Gaspar et al., 2003). Women frequently become caregivers due to gender disparities, as they are more inclined than men to reduce their work hours or stop working entirely in order to assume caregiving responsibilities (Gerain & Zech., 2019).

Caregiver Challenges with Navigating Healthcare System

Part of an informal caregiver's role is to act as the intermediary between care teams and the patient, in working with doctors to make sure strategies are best being implemented to care for patients (Beach et al., 2018). Unfortunately, caregivers experience many challenges in this role as a liaison with healthcare professionals. Caregivers frequently have difficulty communicating with healthcare providers and navigating the healthcare system, which increases

their risk of burnout due to insufficient support from healthcare providers (Gerain & Zech., 2019). This leads to a lack of coordination of services and limited access to education and resources to help family members ease the burden of caring for loved ones (Szlenk-Czyczerska et al., 2020). When caregivers are unable to work well with healthcare providers, this also leads to reduced quality of care provided to care recipients.

Occupational Challenges in Caregiving

Becoming an informal caregiver is extremely challenging, as those tasked with the role must process the emotional strain of a loved one's illness while also taking on the stress of responsibilities in a new caregiver role. Family caregivers usually provide care long term, working an average of 24 hours per week over 4.5 years in their caregiving role (Utz, 2002). The negative emotional and physical toll on caregivers is due to high physical demands, emotional strain, financial stress, isolation, reduced interpersonal relationships, limited free time, and high time commitment, which lead to an overall reduced quality of life (Gaspar, 2023). These challenges then can lead to caregiver burnout, which can have lasting negative physical, emotional, and psychological health problems for the caregivers. These include the higher likelihood that caregivers neglect their own physical health and wellness as they are focused on providing for the care recipient, which in turn increases their likelihood of developing negative health conditions (Gaspar et al., 2003). Physical health deterioration is most likely due to increased stress hormones, poor eating habits, increased alcohol consumption or drug use, as a result of caregiver strain, and occurred most often in caregivers who were older and female (Lewis et al., 2016). McAtee et al. (2021) found that those caring for individuals with dementia were more likely to experience negative mental health impacts leading to depression and anxiety, which further increased their risks of developing diabetes, heart disease, and ulcers.

Groups Most Likely to Get Caregiver Burnout

Groups of caregivers who are more likely to be at risk of negative effects from informal caregiving include women, people with health conditions, and those with low education levels (Gaspar et al., 2003). Caregivers who provide care for longer periods and for longer daily hours, as well as those with highly dependent care recipients, were more likely to experience caregiver burden (Gaspar et al., 2003). An informal caregiver who is of lower income, unemployed, and has less support from friends or family is more likely to experience higher anxiety rates (Allen et al., 2022). Caregivers who had children of their own were also more likely to have higher levels of burnout, as this increased responsibility added to their stress levels (Gerain & Zech, 2019). The mental attitude that caregivers take to their role had a large impact on their burnout rates as those who acted more helpless and less optimistic experienced higher stressors (Gerain & Zech, 2019). Beach et al. (2018) found that caring for seriously ill, high-need, and high-cost patients was more likely to lead to negative health outcomes of caregivers, as this required increased demands of the caregiver's time and attention. These higher need care recipients often included older adults with three or more chronic diseases and functional limitations, those with probable dementia, and those at the end of life (Beach et al, 2018).

Care Recipient Impact of Caregiver Burnout

When informal caregivers experience burnout from their role, this impacts the level and quality of care they provide. Gaspar et al. (2023) found that when caregiver burden led to depression, they were less likely to provide quality care to the care recipient, and in some instances abandon their role altogether. Caregiver burnout increases the likelihood of mistreatment towards care recipients, which can lead to instances of physical or verbal abuse (Gerain & Zech., 2019). Prior studies have shown that on a monthly basis, approximately 20% of

disabled older adults reported experiencing unmet needs for assistance with Activities of Daily Living (ADL) (Beach et al., 2018). Among other factors, Beach et al. (2018) found that caregivers who provided over 100 hours of monthly care and those who had emotional and physical challenges in their role were more likely to have care recipients with two or more unmet daily living needs. This was especially true for caregivers providing care to patients with high care needs and costs associated with the care (Beach et al., 2018). A longer length of care and increased stressors of caregiving negatively impacted the quality of care provided to the care recipient. When patients have unmet needs, this increases their need for additional hospitalization visits and poorer health outcomes, as well as increased healthcare costs for both the individual and for the healthcare system as a whole (Beach et al., 2018).

Long Term Mortality Risks

If informal caregiver burnout is not addressed, caregivers may suffer long term mental health problems and physical health issues. If left untreated, the negative physical health and emotional health of caregivers can cause long-term negative consequences to their overall well-being and the possible risk of mortality. A study by Schulz et al. (1999) found that caregivers of spouses, specifically those who experienced high stress and burnout rates, faced a 63% higher risk of mortality when compared to their non-caregiving counterparts. Conversely, caregivers in the study who did not experience burnout showed no increase in mortality rates when contrasted with non-caregiving groups (Schulz et al., 1999). This underscores the importance of identifying caregivers under mental or emotional strain, particularly among elderly spousal caregivers, to prevent their higher mortality risk rates.

Financial Challenges in Caregiving on the Individual Level

The rise in informal caregiving causes individual and family financial hardships as caregivers often need to reduce their work hours, take unpaid time off from work, or even quit their jobs. Those most likely to reduce their work hours or leave the workforce altogether include low-income individuals, minorities, and women (Feinbeg et al., 2012). One national survey found that 19% of people who retired early did so due to caregiving responsibilities (Lewin et al., 2016). This financial constraint leads to a higher likelihood of stress and burnout, and an increase in poverty levels, especially in lower income populations (Pristavek & Luth, 2020).

Approximately 25% of family caregivers self-report financial challenges when placed in an informal caregiving role, with these stressors being higher for Black/African American and Hispanic/Latinx caregivers when compared with White caregivers (Estrada et al., 2022).

Caregivers who provide longer hours of care and those who live farther away from those cared for are at increased risk for financial stress and strain (The Lewin Group, 2016). Unsupportive employer policies contribute to the financial challenges that caregivers face. The Lewin Group (2017) found that fewer than 25% of employers approved employees' requests for flexible work schedules or employee assistance services when they needed to care for a sick family member.

The average lifetime financial burden on family caregivers is estimated at approximately \$304,000 in lost wages and benefits for those aged 50 and older who leave the workforce to care for a parent (The Lewin Group, 2016).

Financial Challenges in Caregiving to Economies

The impact of informal caregiver stress and burnout also has a negative financial impact on economies. Each year, informal care is provided by approximately 18 million Americans to older adults, which equates to 37 billion hours of care, or the equivalent of \$470 billion in unpaid

labor (Pristavek & Luth, 2020). The direct impact on employers is the loss of approximately \$33.6 million due to lower productivity rates of full-time employees who take extended time off work, are distracted in their work, reduce their work hours, and leave the workforce thereby requiring employers to hire a replacement (The Lewin Group, 2016). When caregivers experience burnout and require more healthcare needs of their own, this ends up costing U.S. businesses about \$13.4 million a year, as employers end up spending eight percent more on their healthcare costs (Feinbeg et al., 2012). As more caregivers experience negative physical and mental health impacts from burnout, this puts further strain on the American healthcare system's ability to provide and support their health needs.

Individual Level Interventions to Address Caregiver Burnout

SMART Program

To address caregiver burnout, many programs have been developed to provide individualized support to caregivers who are at risk of experiencing negative health consequences from their role. One such program that takes a social cognitive theory approach to caregiver burnout reduction is the Stress Management and Resiliency Training, Relaxation Response Resiliency Program (SMART Program), an eight-week program aimed at reducing stress levels of healthcare professionals through an individualized intervention approach (Dossett et al., 2021). This program was effective in teaching stress reduction skills, including mind-body, cognitive, and lifestyle techniques as well as increasing resilience in healthcare providers' ability to deal with stressful situations as well as an improvement in their job satisfaction (Dossett et al., 2021).

REACH Program

Another program that followed the social cognitive theory model is the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project, which utilizes a provider-patient approach to support caregivers of individuals with Alzheimer's (Burns et al., 2003). The REACH I program found that active intervention techniques, such as role playing, were more effective at reducing caregiver depression and burden rates than solely educating individuals on this topic (Belle et al., 2006). One study found that a 24-month individualized REACH intervention program that provided caregivers of dementia patients guidance from healthcare professionals on managing the care recipient's behavioral issues as well as individualized support for coping with their own challenges, such as learning relaxation techniques and stress management, led to better overall wellness and reduced burnout symptoms (Burns et al., 2003).

An adapted version of the REACH program, REACH II, focused on caregivers' self-management and cognitive behavioral strategies to manage their stress levels, through a personalized approach based on individual caregiver self-assessments (Belle et al., 2006). REACH II included intervention visits to the caregiver's home where they were taught how to improve self-care, increase healthy habits, problem-solve challenges with caregiving, and care management skills, along with telephone-based sessions regularly (Belle et al., 2006). Based on results from 494 participants who underwent the REACH II intervention or an education-only approach, participants showed promising results including a significant improvement in overall perceived health after six months of the intervention (Belle et al., 2006). Although the REACH programs had some success, there were limitations to their studies. This included the fact that the study did not take into consideration the characteristics of the caregivers that impacted their level of burden, which included gender, ethnic background, level of education, and their relationships with the patient (Gitlin et al., 2003). For example, African American caregivers had lower

quality of life improvement indicators when compared to their White or Hispanic counterparts (Belle et al., 2006). Further research and evaluation is needed to address how these caregiver characteristics, such as ethnicity, impact caregiver burden. The REACH program also did not address other challenges related to caregiving burden, such as disruptions in their daily routines, feelings of social isolation, changes in work and financial stress, and neglect of their personal health (Gitlin et al., 2003).

Community Level Interventions to Address Caregiver Burnout

Veterans Affairs (VA) Caregiver Support Program

The Department of Veterans Affairs (VA) has developed comprehensive programs to support caregivers of U.S. veterans through a wrap-around approach. In 2010, two U.S. programs were enacted to provide support to veteran caregivers: the Program of General Caregiver Support Services (PGCSS) and the Program of Comprehensive Assistance for Family Caregivers (PCAFC) (Shepherd-Banigan et al., 2020). PGCSS offered services such as respite care, support groups, and peer mentoring for veteran caregivers (Shepherd-Banigan et al., 2020). PCAFC provided financial aid for expenses like transporting veterans to medical appointments, mental health care, health insurance, a stipend, and transportation support (Shepherd-Banigan et al., 2020). One limitation to the program is that PCAFC does not include all veterans, but only those who had an injury when serving in the military (Shepherd-Banigan et al., 2020). The VA Mission Act of 2018 expanded PCAFC by broadening eligibility criteria, offering financial counseling, and extending service durations (Shepherd-Banigan et al., 2020). Some challenges to the VA programs are they did not address caregivers' stress related to the patient's healthcare

team neglecting the needs of the caregiver to support their family member (Shepherd-Banigan et al., 2020).

National Family Caregiver Support Program (NFCSP)

In the U.S., various programs have been developed to support older adults at the community level. The Older Americans Act (OAA), enacted in 1965 by Congress, aimed to provide social support services for older adults with the goal to help them age in their communities and live more independently (Thomas, 2014). The Title III-E National Family Caregiver Support Program (NFCSP) was passed by the 106th Congress in 2000 and was a reauthorization of the OAA. NFCSP became the first federal initiative in the United States designed to provide comprehensive support to informal caregivers of older adults and was funded under the Administration for Community Living (ACL) (The Lewin Group, 2016). States supplemented 25% of the cost for the program and provided five key areas of family caregiver support which included: support services access, counseling, training and support groups, respite care, and additional supplemental services (The Lewin Group, 2016). Funding for each state was based on the percentage of older adults above a specific age, with the annual budget since 2008 being in the \$154 million range (The Lewin Group, 2016). States were given flexibility to use their funds as needed to address the specific caregiver needs of their resident population. Challenges to the NFCSP included limited funding and variation in program implementation across states, as well as inconsistent evaluation tools which made it difficult to measure program effectiveness and the best use of funds. Also, the program did not address the challenges that caregivers had in working with healthcare providers in improving coordination of care. Lastly, some states had difficulty providing outreach and awareness of the program offerings to the target population.

Policy Level Interventions to Address Caregiver Burnout

State Paid Leave Policies

In response to the lack of a national paid leave policy in the U.S., several states have created their own paid leave policies to support family caregivers for both caring for a newborn child and for caring for someone due to medical reasons. As of 2023, 13 of the 50 U.S. states as well as Washington D.C. have a paid family medical leave policy (U.S. Department of Labor, 2024). These states provide a varied amount of paid leave, ranging from five to twelve weeks (Jefferson, 2023).

California Paid Leave Policy

California was the first state to offer Paid Family Leave in 2004, by providing six weeks of partial pay to individuals caring for seriously ill relatives and to new parents bonding with their newborns (Rossin-Slater et al., 2013). In July 2020, this amount of paid leave, equating 60-70% of one's weekly wage, increased to eight weeks of covered paid leave (Tobin-Tyler et al., 2021). California's policy requires caregivers to receive a medical certification from the care recipient's healthcare provider after they apply for paid leave through the Employment Development Department. One limitation of the California Paid Family Leave Act is that it does not provide job protection for individuals, and instead are covered by FMLA or the California Family Rights Act which only provides job protection for employers with 50 or more employees (Tobin-Tyler et al., 2021). In addition, from 2004-2014 only 10% of the state's PFML applications were to care for a sick family member, versus 90% to care for a newborn, which highlights a gap in caregivers' awareness of this program's existence (Tobin-Tyler et al., 2021).

Massachusetts' Paid Leave Policy

Massachusetts' Paid Family and Medical Leave Law was passed in 2018 and includes job protection and provides 12 weeks per year for paid leave with the maximum weekly amount of \$850 (Tobin-Tyler et al., 2021). Massachusetts' policy, similar to California's, also requires a medical certification that the caregiver must receive from the care recipient's healthcare provider, which has proven to be an additional form of stress for caregivers to complete (Tobin-Tyler, et al., 2021).

Family Medical Leave Act (FMLA)

Currently, 19 out of 36 Organization for Economic Cooperation and Development (OECD) countries offer paid family leave to care for a sick family member, with varied amounts of time and pay offered by each (Bipartisan Policy Center, 2020). The United States is one of the few OECD countries that does not provide this paid leave. The United States passed the Family and Medical Leave Act (FMLA), signed by President Clinton, in 1993 which provided job security and benefits for up to 12 weeks of unpaid leave for eligible employees working in large companies or public agencies to care for a sick family member (Slater et al., 2013). Although the act was meant to support family caregivers, there were many challenges to the uptake and effectiveness of FMLA due to it being unpaid and not including many employee groups. Only 60% of the workforce met the eligibility criteria of FMLA as limitations exist: for example, private employers with less than 50 employees were not required to provide FMLA benefits to their employees (Park & Robinson, 2020). Also, because this employment leave was unpaid, many individuals were unable to take advantage of FMLA (Park & Robinson, 2020). One study found that 64% of employees who required leave from work did not utilize FMLA because it was unpaid and of those who did take leave, about half returned to work earlier than intended due to financial constraints from the unpaid time off work (Chung et al., 2012). Goodman et al.

(2021) found that workers who took unpaid leave were more likely to have financial challenges, stressors, and lower quality of life when compared with those who took paid leave. Additionally, there was often an issue of employer discrimination against employees who utilize FMLA leave, such as being treated poorly when returning to work, being pressured to return to work, or losing job security (Park & Robinson, 2020). Furthermore, lack of awareness about FMLA benefits and its eligibility criteria discouraged many individuals from utilizing FMLA who would otherwise qualify (Park & Robinson, 2020).

Recommendations

Theoretical Approach to Recommendations

To reduce caregiver burnout, the socioecological model approach recommends a multi-level tier of support, with recommendations at the individual, community, and policy levels. This multi-level of support should include caregiver education and training, knowledge of and access to resources, counseling support, partnerships with healthcare providers, and financial support to be most effective at reducing caregiver burnout. Additionally, these multi-level supports need to be integrated and comprehensive to be most effective and to address the challenges on all levels for caregiver burden.

Individual Level Recommendations

The first individual level recommendation is focused on educating individuals and the public about informal caregiver burnout by expanding and improve existing caregiver toolkits, such as the Caregiver Action Network's "The Family Caregiver Toolbox" (Caregiver Action Network, 2024) and the AARP Caregiver Resource Guides, which vary by state (AARP, 2024). Educating caregivers on how to best provide care is crucial to help reduce caregiver burnout rates, as evident from the REACH program results (Burns et al., 2003). The new toolkits should

include all of the following information: education on the caregiver role, knowledge of care recipient diagnosis and how to support, financial, resources, community resources/organizations, and how to work with healthcare professionals and navigate the healthcare system. The toolkit needs to be promoted nationwide to increase awareness of the challenges caregivers face, increase accessibility, and educate individuals about the valuable resources available.

One way to disseminate the caregiver toolkit is to partner with existing caregiver support organizations to disseminate the information, such as the Family Caregiver Alliance, AARP, VA, FMLA, National Alliance for Caregiving, and The Administration for Community Living. Additionally, including the toolkit as a resource in the FMLA correspondence to caregivers is a great strategy to reach the target population when they start their caregiving responsibilities. The utilization of social media platforms can help promote the toolkit and increase public awareness of caregiver burnout through sites such as TikTok, Instagram, and YouTube. The toolkit should also be available in many formats, and by creating a pre-recorded version, this will complement the written materials and increase reach and engagement. In order to engage the diverse population of caregivers in the U.S., the kit would need to be translated into several languages as evidenced by the VA's Caregiver Support Program, which translated their training into Spanish and had their workbook available in 11 other languages (VA Caregiver Support, 2023).

The second individual level recommendation is to improve existing caregiver burnout models and implementation of existing intervention programs and support groups. These interventions need to have a tailored program structure and curriculum to address the specific needs of each distinct caregiving context, to increase effectiveness in reducing caregiver burnout. The Informal Caregiving Integrative Model, an approach to improve models and approaches to address caregiver burnout, recommended the need to consider the caregiving environment, the

characteristics of the caregiver, and their sociocultural background in order to best understand and treat caregiver burnout (Gerain & Zech., 2019). Currently, there are many ongoing challenges in the research and evaluation of caregiver intervention programs, which included few well-controlled randomized trials, narrow scope of outcomes studied, small sample sizes, geographic constraints, inadequate representation of racial or ethnic diversity, and a lack of comprehensive interventions with multi-components (Belle et al., 2006). To address this challenge, there needs to be increased program evaluation and assessment to identify the unique support needs of each caregiving group, which include socio-economic status, gender, relationship to the cared for, ethnicity, and the context of the person receiving care. As discussed by Pinquart and Sörensen (2005), while African American caregivers had lower levels of caregiver burnout and depression when compared to White caregivers, Hispanic and Asian-American caregivers displayed higher levels of depression than their White non-Hispanic counterparts. Belle et al. (2006) found that Black/African Americans did not respond as well to the REACH multicomponent intervention program as their White or Hispanic counterparts. According to Estrada et al. (2022), Black/African American and Hispanic/Latinx caregivers were found to face greater financial challenges, including heightened stress and strain, in their caregiving role. Different support programs need to be developed for caring for someone with dementia or other diseases/illnesses, as the level of care needed by the care recipient greatly impacts the stress level of the caregiver (Beach et al., 2018).

Community Level Intervention and Program Recommendations

At the community level, better coordination of care between healthcare professionals and caregivers is needed, along with the establishment of better healthcare systems to engage caregivers in the care process, so they are provided with the necessary support, education, and

training. In the U.S., recommendations include enhancing existing toolkits for physicians on how to work better with family caregivers, such as the Family Caregiver Alliance “Caregivers Count Too! Toolkit” (Family Caregiver Alliance, 2024). This updated physician’s toolkit should then be promoted using the same approach as the Caregiver Toolkits mentioned previously.

Improving care coordination is key to supporting caregivers’ health and wellness, as the REACH program evaluation found that caregivers who worked with primary care physicians showed improved results in caregiver burnout reduction (Burns et al., 2003). In particular, caregivers caring for high needs and high-cost patients would benefit most from healthcare providers partnering with them to provide care, educate them, and support them in their role (Beach et al., 2018). According to Gaspar et al. (2003), increased access to social support through healthcare providers served as a protective factor to reduce caregiver burnout rates and to improve the quality of care.

One model the United States can adopt is that of Japan's Long-Term Care Insurance (LTCI) program, which supports older adults by creating care plans with healthcare case managers after an assessment, and providing in-home care assistance (Yamada & Arai, 2020). Through the LTCI program, an Integrated Community Care Systems (ICCS) Care Manager provides advice and support, service coordination, referrals to housing and rehabilitation services to support older and disabled adults (Szczepura et al., 2023). These wrap-around programs and services provided in the communities where those needing long-term care live are helpful to reduce burnout rates as they work collaboratively with caregivers and treat them as an important part of the care team.

Policy Level Recommendations

National Paid Leave Policy

On a policy level to help address the financial hardships that many informal caregivers face, the United States should develop a national paid family leave policy. This can be achieved by expanding upon the best practices of existing state paid leave policies and the best practices of other countries with successful leave policies. In Japan, the Child Care and Family Care Leave Act allows employees to take up to 93 days of paid leave to care for a family member (Niimi, 2021). In Europe, Austria, Sweden, Czech Republic, and Italy, informal caregivers are provided three months of paid leave (Bihan et al., 2019). Goodman and Schneider (2021) observed that when service workers received paid leave to care for an ill family member, they were more likely to pay their bills, experience fewer financial hardships, have better sleep quality, and maintain a better overall well-being. This was also true for individuals who had paid leave for their own illnesses. Additionally, one study found that when middle-aged female workers had access to Paid Family Medical Leave (PFML), they were more likely to retain their jobs and experience less financial strain (Goodman et al., 2021).

Expand FMLA Eligibility

Another recommendation is that the U.S. needs to expand FMLA's eligibility definition, as several states' paid leave policies currently include close family members such as siblings as eligible care providers. Internationally, 8 OECD countries have no limitations for who is allowed to take care of family members for paid leave as their definition of family members is broad (Raub et al., 2018). FMLA should expand to cover all close family members, such as siblings, to expand the network of support options to provide care (Raub et al., 2018), which in turn will

provide families greater flexibility in determining the best informal care arrangements for their loved ones.

Job Flexibility and Security

Another area that FMLA should improve is greater job flexibility and job security, as this has a strong impact on caregiver burnout related to financial stress. Currently, Japan's leave policy requires employers to provide flexible work arrangements and job protection (Niimi, 2021). The benefits to a national paid leave program, with Japan as an example, is that more caregivers are able to maintain employment and therefore have more financial security when providing informal care (Niimi, 2021). Currently Austria, Czech Republic, England, Finland, France, Germany, and Sweden provide flexible work options, including part-time work schedules, for informal caregivers (Bihan et al., 2019). In Germany, caregivers are allowed to work part-time for up to 24 months if they work in a company with 25 or more employees and they receive 6 months off work (Kanda et al., 2022).

Additional Financial and Economic Benefits

Another recommendation is for the United States to offer other financial and economic benefits to caregivers such as caregiver allowances and insurance or pension benefits, to alleviate their financial burden. Currently, the VA provides travel benefits to caregivers to bring patients to appointments and a monthly stipend to the primary caregiver of a veteran with an eligible injury that occurred in the line of duty (U.S. Department of Veterans Affairs, 2013). In Sweden, the Family Care Leave program allows the government to pay a family member, under 65 years old, a similar salary and social security benefits as they would pay if they hired an outside caregiver (Kanda et al., 2022). In the UK, a caregiver allowance is provided to caregivers in the amount of £62.1/week, with eligibility requirements based on one's weekly income (Kanda et

al., 2022). In France, the Family Support Leave Act requires the government provision of pension reserves and payment of employee medical insurance premiums during caregiver leave, which can last up to a year (Kanda et al., 2022). The UK provides a Carer's Credit exemption where eligible family caregivers can receive national health insurance free of charge (Kanda et al., 2022). In the United States, the VA provides caregivers free health insurance through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) (US Department of Veterans Affairs, 2013). Goodman et al. (2021) noted that a comprehensive safety net that included universal health insurance among other supports could reduce the financial burden for individuals who need to take leave from work to care for a family member. Therefore, these additional financial and economic supports can play a crucial role in helping to reduce caregiver burnout rates in the United States by reducing the financial stress of caregivers.

NFCSP Program Structure Reevaluation

In order for the NFCSP to be more effective in supporting caregivers, it needs to reevaluate its program structure as well as increase its funding. The NFCSP should model its program requirements to those of the VA Caregiver Support Program, so it more closely aligns with the VA's comprehensive approach to prevent caregiver burnout. This can be done by creating and expanding upon the requirements for each state's NFCSP funded caregiver support programs, so they offer the scope of programs and services that the VA program provides. These should include: stipends, respite, health insurance, peer support groups, financial services, mental health, legal and financial planning services, health coaching, virtual psychotherapy counseling, and patient travel support (VA Caregiver Support, 2023). Funding for the NFCSP needs to be increased to ensure more Americans have access to its breadth of services, as current state and local funding and programs offered vary considerably. Better assessments and evaluation tools

need to be developed for NFCSP so funds can more effectively address the diverse needs of different populations of caregivers in preventing burnout, which can vary based on factors such as gender, SES, and ethnicity.

Funding and Costs

One of the largest challenges to implementing caregiver burnout interventions is addressing how they will be funded, especially the recommendation to expand FMLA into a national paid leave policy. If enough legislative support and advocacy is achieved, the federal budget can allocate funds to support a paid leave program, either by relocating existing funds or by increasing tax rates for higher income earners and reducing tax loopholes. The U.S. government can follow guidelines for how states are currently providing paid leave through expanding on their disability insurance programs, or through a payroll tax, either on the employer or the employee (Tobin-Tyler et al., 2021). The government can offer tax credits to companies that offer paid leave policies, as a way to incentive and increase company participation. Other strategies include looking to other countries for ideas, such as in Japan where the long-term care insurance (LTCI) system requires all citizens over 40 to pay a premium (covering 50% of the program) and taxes covering the other 50% of the program (Yamada & Arai, 2020). Alternatively, a strategy such as in Canada can be adopted, where employees and employers pay into an Employment Insurance (EI) to be used for when they need to take paid leave (Khan et al., 2023). On a company-wide level, employers can provide more Employer Assistance Programs or allow the use of HSA/FSA funds for these program utilizations. Some additional strategies to increase funding for NFCSP are through states raising funds from nonprofits and philanthropies to cover additional program costs, or by offering corporations tax incentives for contributing to these programs. With the caregiver ratio projected to decline from

7 caregivers per older person in 2013 to approximately 3 by 2050, the urgent need for increased federal funding to address the growing gap is becoming ever more crucial (Redfoot et al., 2013).

Discussion

Impact of Recommendations

The impact of the Caregiver Toolkit and its widespread distribution are that caregivers will be better equipped to handle the challenges of their role and prevent burnout, as they will have a comprehensive guide to follow. McAtee et al. (2021) determined that caregivers of family members with dementia often had limited knowledge or training in how to provide care which resulted in high levels of caregiver burnout rates, which this guide would address. The REACH study's multicomponent approach found that by providing caregivers with education and skills training on caregiving, this made them feel more confident in their role, reduced their stress levels, enhanced their caregiving abilities, and improved the quality of life for the care recipient (Belle et al., 2006). Another positive impact of distributing the Caregiver Toolkit is increased public awareness and understanding of the challenges caregivers face and their support needs, potentially leading to increased advocacy and legislation to fund these programs.

The positive impact of improving intervention programs to target the diverse needs of caregiving populations, is that programs will be more effective at identifying, reaching, and supporting high risk groups of caregivers for burnout. Gitlin et al., (2003) determined through their analysis of the REACH program that specific caregiver groups, including men, spouses, and African Americans, did not show positive results from their interventions; they concluded that further research was needed to investigate the causes of this disparity. Funds for these programs will be better utilized to show results for diverse caregiving groups once better evaluations and assessments are put in place to improve program designs.

Through redefining coordination of care, physicians and healthcare providers will be better trained with knowledge of how to better work with caregivers. Care integration will foster better coordination and communication among healthcare providers in recognizing informal caregivers as partners and part of the care team. Better coordination will lead to more positive health outcomes for both the caregiver and the person being cared for as family caregivers often serve as intermediaries between doctors and patients, playing a crucial role in executing care plans, promoting preventive health measures, and encouraging better health outcomes (Beach et al., 2018).

Another positive impact of these recommendations is improved care recipient health outcomes. Reduced stress of caregivers means that patients will receive higher quality care, have better health outcomes, and quicker recovery times. When care recipients receive better care and have a greater number of their ADL needs met, this reduces their need for additional hospitalizations, readmissions, and emergency department visits often due to falls and injuries (Beach et al., 2018). Patients can choose to have their care take place more comfortably at their home instead of in a facility when caregivers are receiving the support they need to continue their caretaking responsibilities. In addition, another positive impact is improved caregiver health outcomes. By providing wrap-around caregiver support through following the VA's model of care, from mental health, training, education, to financial assistance, programs will be able to address caregivers' diverse needs. Increased funding and better evaluation tools will make better use of program funds from state and federal dollars to support NFCSP expansion.

Reducing caregiver burnout will also lead to healthcare system cost savings in the United States with less funding needed to address the negative physical and mental health impact of caregiver burnout. This includes reduced hospital and ER visits from patients receiving better

care from caregivers who are getting the support they need. Improving the quality of care provided by caregivers reduces government expenditures on the most costly aspects of health and long-term care, which includes older adults with three or more chronic diseases, dementia, and those nearing the end of life (Beach et al., 2018). Less taxpayer money is subsequently required to fund nursing homes, other care institutions, or foster care through Medicare/Medicaid. Increased closer collaboration between caregivers and healthcare providers can potentially reduce healthcare costs and utilization by enhancing patient health (Beach et al., 2018). In 2017, the economic value of informal caregivers was three times greater than Medicaid expenses on services and supports related to long-term care in the United States (Allen et al., 2022). By supporting informal caregivers to stay in their roles longer, this reduces the amount the government needs to allocate for Medicaid expenses. The positive impacts of a paid leave policy include additional financial resources to prevent poverty, the ability for caregivers to provide longer duration of care, reduced stress levels on caregivers and their families, and the protection of jobs and improvements to the economy and workforce.

Limitations

One of the limitations to these recommendations is attempting to change the United States healthcare system and culture. In the current state, primary care physicians are often too busy to coordinate and work with caregivers in an increased capacity, which could hinder collaboration. In contrast, Japan, which offers universal healthcare, has a more structured national approach to how healthcare providers partner with caregivers through LTCI, and focuses a lot on preventative measures and community-based care. Since Japan's model is a universal healthcare system that the government controls, it is easier to provide continuity among the quality of services that providers offer. In contrast, the United States is based on private

health insurance coverage with healthcare providers operating very independently. This makes it difficult to require a consistent standard of collaborative care across all healthcare providers, as the services and levels of care vary by state and region and are funded differently.

The political impact of increasing financial support programs for caregivers, through increasing paid leave programs, is that this will create more party divisions. Determining if it is a state or federal responsibility to support caregivers with paid leave and other economic support can become a divisive political issue. The party in power, either Democratic or Republican, and the majority in Congress will impact whether the federal government or individual states will fund programs to support informal caregivers. If federal funds are to be used to fund paid leave, this would require raising taxes, most likely on higher earners, which would more likely be supported by Democrats versus Republicans. For example, FMLA was vetoed by George H.W. Bush two times, a Republican, whereas Bill Clinton, a Democrat, passed it in 1993. If paid leave is offered nationally, the definition of a family unit will become politicized, causing inconsistencies with eligibility for same-sex couples by state.

Moreover, the implementation of a national paid leave policy will depend on raising public awareness of the issue as a critical public health concern and prioritizing it legislatively. Given the significant federal deficit and budget shortfalls faced by many states, substantial legislative backing would be necessary and challenging to secure funding. Japan's system of requiring individuals to pay long-term care insurance (LTCI) premiums based on age and income may not be adoptable in the United States, where the healthcare system is primarily managed by private insurers and would require a major healthcare structure overhaul. Currently, the United States relies on Medicaid and Medicare for limited support with paying for long-term care needs, with additional funding coming from a mix of federal and state sources. Increasing funding for

caregiver support programs in the United States faces many challenges due to the complexity and privatization of the healthcare system, when compared to Japan's more standardized, government-run approach.

Next Steps

Increased public awareness concerning the needs of informal caregiver and burnout is necessary to enhance collaboration with existing organizations, advocacy groups, and government agencies. The recommendation for the "Caregiver Toolkit" expansion and distribution provides a starting point to increase public awareness and focus on this public health issue. Existing agencies that focus on supporting caregivers need to expand on their collaboration efforts to help change programs and policies in the United States. These include the National Alliance for Caregiving (NAC) which was formed in 1996 as a national coalition of over 50 healthcare companies, nonprofit public health organizations, and financial service representatives to address the needs of caregivers nationwide (National Alliance for Caregiving, 2024). On June 24, 2024, The NAC launched the Caregiver Nation Network, a partnership among leaders from 10 states to advocate for improvements in state and federal caregiving policies in the United States (National Alliance for Caregiving, 2024). Another important recent legislation was in 2018, when Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (Pub.L. 115-119), which required the Department of Health and Human Services (HHS) to create a National Strategy to Support Family Caregivers by 2022 (The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council et al., 2022). The adoption of the national strategy is a promising start to raising awareness of the insufficient resources allocated to family caregivers on a national level. The next step is applying the country's funds, resources, and attention to implementing the strategies.

These initiatives should continue their collaborative work to increase funding, so caregiver burnout becomes a higher legislative priority.

The U.S. government should prioritize increasing funding and expanding federal programs to provide comprehensive support for caregivers on a national level. This system of comprehensive support for caregiver recommendations should include education, training, support groups, financial assistance, respite service, and connections to resources. Increasing paid family leave programs and eligibility, preferably on a national level and not just state level, and financial support for caregivers need to be implemented to support this crucial population of the unpaid American workforce. NFCSP needs to continue to improve its effectiveness through streamlining regional services and creating better program evaluation, which is something that has not been prioritized by the U.S. government. Better assessment tools should be developed to best address the specific and unique needs of each caregiving population and varied circumstances.

The American healthcare system needs to reassess how it is structured and prioritize coordinated care models with reduced physician caseloads. This will enable a more collaborative and supportive approach to care between caregivers and physicians. Exploring cost-effective, innovative ideas to support caregivers is essential by looking more into other countries best practices of caregiver support. For example, in France, coworkers can donate unused paid leave to colleagues who are acting as a family caregiver or require support themselves (Kanda et al., 2022). These innovative ideas for how to efficiently and effectively address this public health crisis will help lead the United States towards a path where everyone gets the care they need, and care providers are supported and appreciated for the invaluable work they do.

Conclusion

This paper has explored the multifaceted issue of caregiver burnout and evaluated current policies and intervention programs designed to mitigate its effects. Existing initiatives often overlook the specific needs of diverse caregiver demographics and lack effective collaboration between caregivers and healthcare providers for care coordination. Programs like the VA offer comprehensive services but are limited to specific populations, while the NFCSP faces challenges such as funding constraints and inconsistent implementation across states. The country has shown promising steps towards prioritizing the needs of older adults and in working more collaboratively to address this issue, through the Caregiver Nation Network and the RAISE initiative. As new programs to support caregivers are developed nationally, it is crucial that the public is well-educated and aware of these resources, so they can best utilize them to prevent caregiver burnout. The absence of a national paid leave policy in the United States exacerbates financial hardships for caregivers. As several states are beginning to implement their own paid leave programs, this will hopefully gain momentum on a national level with policymakers, as they see the many benefits that supporting caregivers financially brings to both the individual and to the economy as a whole. As most developed countries in the world offer better quality paid leave and support for informal caregivers, America needs to catch up and be a model of positive change and lead as an example for others in prioritizing the health of its citizens and their overall wellbeing.

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Appendix

MPH Competencies

Competency
Public Health & Health Care Systems
5. Compare the organization, structure, and function of health care, public health, and regulatory systems across national and international settings
Policy in Public Health
14. Advocate for political, social, or economic policies and programs that will improve health in diverse populations
15. Evaluate policies for their impact on public health and health equity
Communication
19. Communicate audience-appropriate (i.e., non-academic, non-peer audience) public health content, both in writing and through oral presentation
Systems Thinking
22. Apply a systems thinking tool to visually represent a public health issue in a format other than standard narrative
Behavioral Health
3. Analyze the impact of chronic conditions and propose strategies to address prevention and management across all levels of the Socioecological Model