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The Impact of COVID-19 on Informal Caregivers in the US

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ABSTRACT

Background: Caregiver burden has negative effects on mental and physical health along with quality of life. Meanwhile, social and physical distancing protocols during the COVID-19 pandemic have created additional impacts on informal caregiving in a rapidly changing environment. Early research over the past year suggests that the pandemic has caused increased caregiver burden as well as caregiving intensity among these individuals. **Purpose:** Our primary purpose in this informational literature review is to describe the impacts of the pandemic on informal caregiver burden and the sudden shift in roles and responsibilities as a result of pandemic-related changes in caregiving. This review will describe emerging effects on various aspects of health among informal caregivers and explore the growing need to support unpaid caregiving during this time. **Methods:** A streamlined search was conducted to fit the scope of this review, with key terms determined to identify relevant publications. Common research databases and up-to-date mainstream resources were utilized. Notably, we focused on research published or released since March 2020, primarily rapidly reviewed studies, to align with the timing of the COVID-19 pandemic in the US. **Results:** Early research suggests that the pandemic has worsened caregiver burden and increased caregiving intensity and hours of care among unpaid, informal family caregivers. Reported health impacts include higher stress, pain, and depression, along with decreased social connectedness and quality of life. Notably, however, COVID-related research generally does not focus on the positive aspects of caregiving, such as its role as a source of purpose in life, creating an opportunity to explore ways to boost certain valuable personal resources among caregivers. **Conclusions:** Informal family caregivers face their own negative health outcomes and distress as a result of greater caregiver burden, intensity, and the changing landscape of caregiving during the ongoing COVID-19 pandemic. Immediate policy and support recommendations should be considered to alleviate informal caregiver burden and provide ongoing resources over the longer term. In addition, future work should explore the potential of boosting positive resources such as resilience and purpose to ease caregiver burden.

Keywords: Older Adults; Pandemic; COVID-19; Informal Caregivers; Informal Caregiver Burden

Abbreviations: PDOH—Personal Determinants of Health

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Introduction

Informal caregivers are generally defined as individuals who provide unpaid care to family members or friends with long-term illnesses, chronic conditions, or other needs [1]. Considered key partners in care coordination and disease management, they provide physical, emotional, social, and practical support, accounting for 70-90% of care given to individuals with frailty, complex conditions, and other disabilities [2]. In the United States, 53 million Americans serve as unpaid informal caregivers to a family member, comprising a critical and central, yet often invisible, piece of the US healthcare infrastructure [1, 3-8]. Informal caregivers are essential to their care recipients, providing crucial services despite a common lack of formal training, social support, and other resources [9]. Estimates suggest the financial value of informal caregiving services was nearly 470 billion dollars in 2013, comprising a significant resource in an overburdened healthcare system [5]. As such, informal caregivers have become frontline healthcare workers, especially during the COVID-19 pandemic with overwhelmed hospital systems [6, 9-11].

Informal caregivers care for aging parents, spouses, and children with disabilities, often

while managing their own chronic health conditions and life transitions [12]. Many informal caregivers are older themselves, with over one-third estimated to have chronic medical conditions that make them vulnerable to health risks including the COVID-19 virus [9, 12]. Meanwhile, studies suggest that women are more likely than men to serve as informal caregivers and are more likely than male caregivers to experience high caregiver burden and intensity [1, 13]. In fact, estimates show that two out of every three caregivers in the US are women, and most women who care for older adults are age 50+ [14]. During COVID-19, estimates show that 78% of those providing unpaid care in the US are female [7].

Caregiver burden is described as the physical, mental, financial, and psychosocial hardships experienced by those providing care for a family member; it encompasses negative impacts on health outcomes and quality of life [1, 15, 16]. Related to burden is caregiving intensity, defined as the amount and type of care provided by informal caregivers to care recipients [1, 17-19]. Even under pre-pandemic conditions, up to one-third of informal caregivers commonly experienced high caregiver burden as a result of their responsibilities [6, 12].

Prolonged caregiving and high caregiver burden often lead to increased anxiety, depression, severe stress, excessive worry, poor sleep, social isolation, loneliness, reduced quality of life, higher mortality rates, and chronic pain [2, 6, 9, 12, 20]. Informal caregivers consistently report rare opportunities to rest, little time for self-care, emotional and physical burnout, and low well-being [7, 8]. Furthermore, already impacted by healthcare disparities, they now face compounded challenges due to the pandemic while continuing to provide care, often at a greater level of intensity [18].

In early 2020, the novel coronavirus, causing COVID-19 infection, triggered an urgent public health crisis in the US, causing extreme disruptions to daily life [1, 21]. Stay-at home orders, safety protocols, and social distancing restrictions have severely compromised social connectedness leading to increased social isolation and an absence of needed resources among informal caregivers [1, 21]. Older individuals have been disproportionately impacted by COVID-19, with higher susceptibility to infection and risk of severe illness, hospitalization, and death [1, 7, 14]. In the US, those age 65+ comprised about 80% of all COVID-19 deaths as of year-end 2020 [7, 14, 22].

Considering the relatively recent nature of the pandemic at the time of this review, few published studies to date have focused on its direct impacts on informal caregiving [1,6].

Nevertheless, emerging research suggests evidence of the significant effects of COVID-19 on unpaid, informal caregivers in the US [1, 17, 18].

Statement of Purpose

The primary purpose of this informational literature review is to describe the impacts of the COVID-19 pandemic on informal caregiving, in part due to the sudden, unexpected shift in roles and responsibilities during this time. This review will examine important reasons for changes in the burden and intensity of informal caregiving in the US. In addition, we will describe emerging effects on various aspects of health and quality of life among informal caregivers and explore the growing need to support unpaid family caregiving during this time.

Methods

For this review, a targeted literature search was conducted to focus on specific topics of interest, rather than a broad systematic review of all areas related to informal caregiving. Per PRISMA guidelines, we conducted a scoping review of literature to provide an overview of new, emerging research on our primary interests—a methodology utilized due to the recent and limited nature of publications specific to caregiving during the pandemic. The following guidelines for qualitative literature review studies were considered [23]:

- Provide a statement of the objective the review addresses.
- Specify the inclusion and exclusion criteria for the review.
- Identify the databases, websites, organizations, or other references searched or utilized.
- Describe the search and selection process to identify the number of studies included.
- Cite each study included along with full reference information.

Source documents for this review were generated from established research databases and search engines, primarily *PubMed*, *Google*, and *Google Scholar*, as well as updated mainstream websites as appropriate to identify recent content. Included were legitimate websites maintained by the World Health Organization (WHO), Centers for Disease Control and Prevention (CDC), and other organizations. Search tools were selected for the scope of publications available, timeliness of research, access to articles, and alignment with standard methodology.

An initial list of search terms was determined by considering key areas of interest, specifically focusing on informal caregiving and caregiver burden during the COVID-19 pandemic, from March 2020 forward. Our search gathered articles published from early 2020 through year-end 2020 in order to align with the onset of the COVID-19 pandemic.

Table 1. Examples of Selected Key Search Terms and Results

Search Terms	PubMed Results (March 2020 On)	Selected for Further Review	Selected for Inclusion
Shift of Informal Caregiving COVID	69	10	8
Informal Caregiving Intensity COVID	99	26	6
Miscellaneous COVID / Caregiving Technology	115	8	4
Informal Caregiving Age 50+ During COVID	124	4	8
Future of Informal Caregiving after COVID	178	4	6
Caregiver Burden Scales COVID	186	12	8
Unpaid Informal Caregiver Burden COVID	187	18	10
Informal Caregiver Solutions During COVID	211	6	4

Total Selected for Inclusion			54

Several search terms returned numerous results, many of which were outside the scope of this review. Thus, we narrowed these results utilizing PubMed's advanced search feature with the main Medical Subject Headings (MeSH) filter. Next, we further streamlined results with the MeSH Major Topic option to identify the most relevant publications for several topics. Titles and selected abstracts were reviewed as needed. Inclusion criteria included original research and reviews with titles and/or abstracts that fit our scope, as well as those focusing primarily on older populations (ages 60+; ages 50-60). Excluded were most articles published outside the US, general research unrelated to the pandemic except for background content on caregiving, as well as those published prior to 2020. Additionally, only articles published in English were selected.

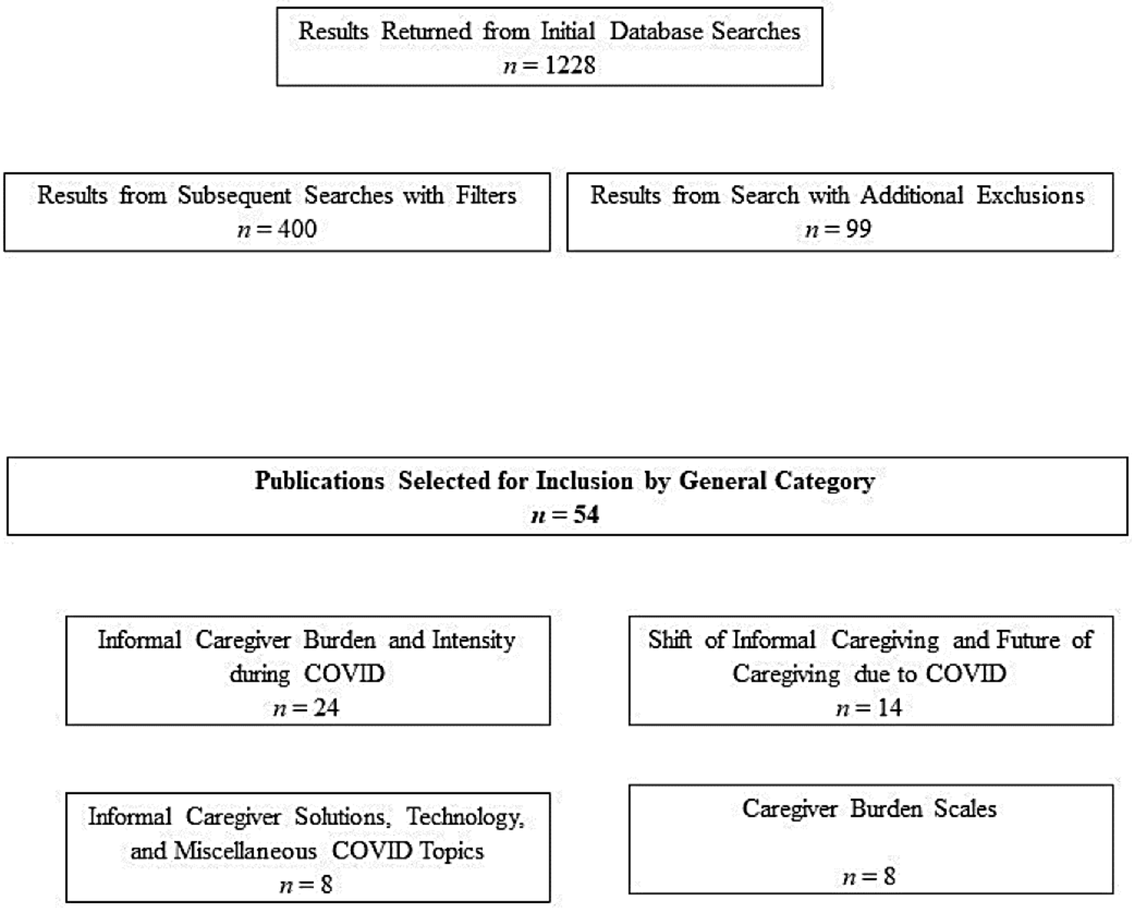
Table 1 displays examples of selected key search terms and the number of filtered results identified for each term; Figure 1 displays the search methods and results by category in a graphical format.

Summary of Results

Assessment of Caregiver Burden

Associations between informal caregiving and high caregiver burden have been studied extensively; however, the impact of shifting levels of caregiver burden during the pandemic have not yet been thoroughly examined as the pandemic still spans a relatively recent period. Considering this timing, few existing measures have been designed and implemented specifically to assess the psychological, social, and mental health impacts of the pandemic among informal caregivers [24, 25].

Figure 1. Diagram Displaying Search Methods and Results



Prior to the pandemic, several existing scales were available to assess caregiver burden and have been utilized in various studies. The early Zarit Burden Interview, also known as the Zarit Burden Inventory, is a widely known self-report measure of caregiver burden, often considered the gold standard for assessment in certain settings [16]. The original version includes 29 questions with responses on a five-point scale (0=*Never*; 4=*Nearly Always*). Abbreviated versions range from 1-22 items, with the six-item version often considered ideal for diagnostic ability and brevity [10, 16, 26]. Another version of the scale measures caregiver burden with 22 items and further identifies two dimensions of burden: objective care and subjective care burden [27, 28]. Objective care burden is measured by the time and expenses dedicated to caregiving; while subjective encompasses self-perception of caregiver burden, including mental, emotional, and behavioral aspects [27].

Elsewhere, the Caregiver Burden Inventory (CBI) is a 24-item, multidimensional measure used to estimate levels of caregiver burden due to caregiving responsibilities, encompassing factors of physical and mental health, social connectedness, and quality of life [1, 29]. Closed-ended questions are divided into five separate dimensions: time dependence, developmental burden, physical burden, social burden, and emotional burden. Each dimension contains 4-5 questions scored on a scale of 0 to 4, with higher total scores (ranging from 0 to 20) suggesting greater caregiver burden [1, 29]. Although this measure has been used primarily with paid formal caregivers, it has demonstrated value as a potential diagnostic tool for informal caregivers as well. The scales described here are the most commonly used in caregiver burden studies, although other similar measures do exist.

Generally, emerging scales designed to assess pandemic caregiver burden primarily focus on anxiety, severe stress, and changes in daily routines [24]. Most notably, the Embracing Carers® organization uses the Carer Well-Being Index to examine various impacts of the pandemic on unpaid, informal caregivers across the globe, encompassing mental, emotional, physical, and financial health [30]. The Carer Well-Being Index was utilized in an online survey study of over 9,000 informal caregivers in 12 countries, with 750 participants completing the US survey in September 2020. This large-scale, comprehensive study provides significant insight into the needs and challenges of caregiving during this time, helping to inform solutions for a post-COVID world.

In other efforts, researchers developed the first scale to assess overall psychosocial functioning among informal caregivers specifically during the pandemic [24]. This scale, the Psychosocial Functioning during COVID-19 (PFC-19) Questionnaire, measures changes in mental health, social interaction, health behaviors, and functioning attributed to the pandemic [24]. Fourteen items assess functioning, or the ability to execute normal activities of daily living (ADLs), with eight remaining items to measure emotional responses and coping strategies impacted by the pandemic [24]. The PFC-19 was validated in an initial online study (N=733) in which nearly 70% of participants were male; 83% were employed full-time; and 66% had been providing care over a relatively short term of one month to two years [24]. Notably, eligible participants were caring for individuals who were age 50 or older at the onset of the pandemic. Results suggest that the two-factor PFC-19 measure may serve as a useful tool in assessing the long-term mental health impacts of COVID-19.

Meanwhile, the Caregiver COVID-19 Limitations Scale (CCLS-9) was developed in both English and Spanish to assess the perceived impact of COVID-19 on informal caregivers [6]. Nine items ask respondents to rate their current difficulties and changes in caregiving on a 1-10 scale [6]. Researchers utilized this scale in an online survey to determine changes in caregiver burden between April and June 2020 (English N=177; Spanish N=144) as compared to January 2020. Among participants in the English survey during early COVID-19, 42% of caregivers were spending greater than 40 hours per week in caregiving duties; 40% of Spanish participants reported the same time commitment. In the early pandemic surveys, 87% of caregivers and 83% of caregivers in the English and Spanish versions, respectively, were female. About one-third in each survey population were older adults themselves, with 39% in the English survey aged 60- 69, and 35% in the Spanish survey aged 50-59 [6]. Findings revealed increased challenges of caregiving as well as higher stress and pain in early months of the pandemic compared to pre-pandemic levels [6].

Early in the pandemic, the 10-item Self-Applied Acute Stress Scale (known as EASE) was developed to assess acute stress among healthcare providers of COVID-19 patients [31]. The EASE measure is designed for paid, formal healthcare workers, but has the potential to determine severe stress levels among care providers for COVID-19 patients, thus enabling streamlined planning for resources, support, and long-term relief. Furthermore, several items could be feasibly adapted for unpaid caregivers, including: “I keep my distance, I resent dealing with people;” “I have completely lost the taste for things that used to bring me peace of mind or well-being;” “Worrying about not getting sick causes me a strain that is hard to bear;” and “I feel intense physiological reactions related to the current crisis” [31].

Emerging Evidence of Increased Caregiver Burden During COVID-19

Early research suggests that the pandemic quickly worsened caregiver burden and increased daily hours of care among informal, unpaid family caregivers caring for a spouse, aging parents, young children at home, or children with healthcare or developmental needs [1, 27, 30]. Commonly reported health impacts among informal caregivers in these recent studies include higher stress, pain, depressive symptoms, sleep problems, and irritability, as well as greater social isolation and decreased physical activity [1, 27, 30]. Emerging evidence suggests that during this time, informal caregivers have neglected their own self-care, routine healthcare needs, and preventive visits [27, 30].

Recent findings from the Embracing Carers study are particularly revealing, showing that in the US alone, 91% of informal caregivers have put their care recipients’ needs ahead of their own during the pandemic [30]. The time commitment required by informal caregiving duties has also shifted. Informal caregivers in the US are facing growing demands, with an average of weekly caregiving hours up from 21 hours pre-pandemic to over 28 hours during the pandemic [30]. In the US, 30% of participants also reported fearing they will spend over 41 hours per week on average devoted to caregiving in the future, resulting from changes in caregiving responsibilities and support during this time [30]. Meanwhile, 65% reported that COVID-19 has made informal caregiving more difficult, with caregiving duties frequently encompassing intense emotional support, meals, transportation, management of medical appointments and finances, and assistance with personal hygiene [30]. As a consequence, caregiver burnout has become overwhelming, with 72% of respondents admitting they feel more burned out than ever, even among younger caregivers [30]. Furthermore, reported impacts include worse mental health (68%), financial health (54%), and physical health (44%) among survey respondents [30]. In addition, 50% of family caregivers are caring for individuals age 65+, with another 20% caring for those age 55-64 years-groups with high risk of severe illness and complications from COVID-19 infection in addition to a high prevalence of chronic conditions [30]. These caregivers must protect vulnerable aging loved ones from the virus, often thrust quickly into this role with little training or preparation.

Notably, informal caregivers express concerns beyond the immediate health threats of exposure to COVID-19. Two-thirds of US respondents in the Embracing Carers study reported fears that the pandemic will cause shortages in medical resources, with 60% stating concerns about access to medications and supplies they need to provide care. Consequently, 66% also worry about the inability to afford the cost of providing care over time [30]. Paid employment pressures were also striking, with 67% of caregivers admitting the need to work full-time in a remote setting while also providing full-time caregiving; furthermore, 56% feared losing their paid jobs due to the time required by caregiving [30]. In regard to caregiving demands, 64% reported that managing technology for telehealth and virtual visits comprised one of their top caregiving responsibilities most impacted by the pandemic [30]. However, 53% admitted the need for guidance and training to effectively use telehealth, online tools, and mobile applications; thus, the critical need for technological support has become urgent [30].

Elsewhere, findings from the Understanding America Study COVID-19 caregiving survey, conducted from April to May 2020, also provides insight into caregiving circumstances early in the pandemic among 4,784 respondents [18]. Notably, the survey explored differences among long-term caregivers (≥1 year), short-term caregivers (≤1 year), and non-caregivers.

Results suggest varying health impacts, with all caregivers experiencing suboptimal mental health and fatigue, but long-term caregivers more likely to report high caregiver intensity and physical symptoms including headaches, body aches, and digestive distress [18]. Supporting the results of these larger studies, smaller investigations provide evidence of accumulating burden among caregivers spanning various demographic characteristics. One such study examined self-reported dynamics in caregiver burden and intensity among informal caregivers of older adults (age 50+) due to COVID-19 [1]. Researchers used the Caregiver Burden Inventory delivered online in June 2020 to estimate levels of caregiver burden and intensity through various dimensions [1, 29]. Among participants (N=835), 53% reported increased caregiver burden with 56% also reporting increased caregiving intensity since the onset of the pandemic [1].

Meanwhile, the younger generation of caregivers has expanded, with 13% of current family caregivers providing care for their children as a consequence of shifting childcare responsibilities due to pandemic safety measures, including school and childcare closures [30]. As caregiving support and resources were halted, many parents faced compound responsibilities, taking on the task of teaching children attending school remotely and navigating childcare; working from home; and caring for aging parents [32]. While research on the pandemic's long-lasting impacts on parents and family structures remains in developmental stages, a few published studies provide insight. Early research findings from US studies show that 24% of parents lost childcare, 35% were struggling to manage caring for children, and at the same time, many experienced financial difficulties with an unemployment rate over 10% in the US [32-35].

In April 2020, an online survey of US adults (N=420) with a child age 18 or younger revealed shifting family dynamics just weeks after many US states began mandatory stay-at-home orders. Parents with the highest levels of self-reported caregiver burden also admitted anxiety over new routines, unknown duration of COVID-19 regulations, closed workplaces and schools, and other stressors [36]. Those reporting increased anxiety and depression also perceived higher stress levels in their children, indicating a potential spillover effect of caregiver burden and other mental health impacts on the family [36]. Similarly, another survey conducted in April-May 2020 among families with young children (age 5 or younger) assessed pandemic stress related to health and finances; child mental health; coping strategies; and caregiver self-efficacy [37].

Results demonstrated high stress among caregivers of young children, along with reduced self-confidence in meeting the family's needs and greater perceived child psychosocial problems[37].

Limited research efforts to date focus on the consequences of caregiving for family members infected with COVID-19. In one select study conducted in March through June 2020, researchers examined caregiver burden among informal family caregivers (N=210) of COVID-19 patients [27]. Results were enlightening, showing a high severity of caregiver burden for 83% and 81%, respectively, among those caring for COVID-19 inpatients and for COVID-19 outpatients at home [27]. Notably, reported caregiver burden in this study was severe, perhaps due to the potential serious nature of COVID-19 and its complications; limited treatments; and high transmission and mortality rates [27].

According to emerging research findings, the serious challenges facing informal family caregivers during COVID-19 generally fall within three main categories: emotional, financial, and healthcare decisions [38]. First, emotional stress reflects the consequences of social distancing and stay-at-home orders, as informal caregivers begin to experience increased social isolation and loneliness, potentially accelerating declining health [38]. Second, informal caregivers face mounting financial stress due to the loss of paid work hours or complete job loss due to caregiving during COVID-19, pandemic economic conditions, and out-of-pocket medical expenses for care recipients [7, 38]. Professional women have been identified as the largest population leaving the workforce at this time due to competing responsibilities including caregiving, childcare, and homeschooling. Notably, previous research demonstrates that women are more likely than men to serve as informal family caregivers, for both aging parents as well as children, and more likely to have higher caregiver burden and intensity overall compared to men [1]. As a third key stressor, balancing important healthcare decisions (such as routine care and needed procedures) while staying safe adds a significant layer of burden during a pandemic [38].

Finally, often overlooked among the multidimensional challenges facing informal caregivers is the financial strain involved in unpaid caregiving. Informal caregivers face the reality of out-of-pocket caregiving costs, often for high-needs care recipients, as well as lost income from reduced paid working hours in order to care for family members [8, 9]. Even prior to the pandemic, up to 45% of informal caregivers in the US reported financial impacts as a result of caregiving duties, a number that has likely grown since the onset of COVID-19 [39]. Furthermore, the complexity of professional work has encompassed job losses, reduced hours, and telecommuting arrangements, adding to potential financial losses and stressful working environments that must be balanced with caregiving roles [8, 9]. Notably, informal caregivers may shoulder accumulating financial burden without adequate financial health literacy, a concept defined as the capacity to understand and apply financial information and resources to make sound healthcare and treatment choices while managing other expenses [40].

Discussion

While few studies to date closely examine the direct impacts of the pandemic on informal caregiving, emerging research suggests growing consequences [1, 18, 38]. The pandemic has created new, unique challenges for informal family caregivers who provide unpaid care, as the burden has quickly shifted to the home while professional providers are consumed by treating patients with COVID-19 [38]. These caregivers have been called the “hidden” care workforce of COVID-19 [38] as well as an essential “shadow workforce” [7].

With high numbers of COVID-19 cases and hospitalizations overwhelming the US healthcare system, many patients have been discharged early to recover at home [27]. Frequently, non-COVID patients with other conditions must also turn to informal caregivers due to an ongoing shortage of formal paid workers, system support, and resources [27, 38].

Complicating this dynamic is the inevitable factor of lacking knowledge, training, and preparedness among family members in absorbing this burden without healthcare system infrastructure and professional expertise [11, 27]. Just a year into the pandemic, a rapidly changing caregiving environment has created a ripple effect of consequences for the family [27]. Notably, it is important to consider how the age of informal caregivers has shifted to include those who are younger, such as middle-aged/50+, with the “sandwich” generation absorbing additional roles.

Meanwhile, findings on gender differences in informal caregiving during the pandemic are beginning to appear in the literature. In US society, the nature of certain career pathways and traditional home and family roles often place much of the burden of managing shifting routines during societal or personal crises on women [41]. Women comprise 90% of early education, healthcare, domestic, and caregiving professions in the US, often earning traditionally lower wages in those roles [41-43]. Consequently, the pandemic has disproportionately impacted these professions; over 60% of jobs lost by late March 2020 in the US due to the pandemic were those employing women [44]. Others who fill frontline roles in healthcare, retail, and service industries faced the choice of remaining in paid positions or staying home with children displaced by school and childcare closures [41]. One early study exploring the impacts of the pandemic on women across four US states highlights these challenges, finding that women experienced greater workplace and employment disruptions, upheaval of daily life, and increased mental burden compared to men [41]. Furthermore, those with children and who lost their jobs during early months of the pandemic were most impacted by these changes [41].

Although female informal caregivers are known to experience higher caregiver burden and intensity, they have also shown to demonstrate higher resilience than male caregivers [1, 45, 46]. Notably, high resilience may be accessed by female caregivers as a buffer to severe stress during times of crisis, potentially explaining why they have reported lower increases in caregiver burden as compared to their male counterparts [1, 27]. Resilience is highlighted as the core of an emerging concept described as personal determinants of health (PDOH), a collection of personal resources that buffer challenges in life and support optimal health outcomes [47]. Even prior to COVID-19, growing perspectives on health outcomes began to shift from a sole focus on negative risk factors to encompass the positive resources within an individual’s control [48]. Recent research demonstrates that older adults with a combination of at least one of these attributes tend to have better health outcomes than those who do not [48]. The most influential of these resources include not only resilience, but also purpose in life, optimism, and social connections, all of which have been compromised by the pandemic [47]. The abrupt absence of strong support systems, roles, and activities; growing anxiety and stress; and the intensifying role of informal caregiving arguably amount to accumulating impacts on these factors [47]. Notably, as policy and practice directions for caregiver support shift as a result of COVID-19, initiatives to focus on boosting the key PDOH during times of crisis could be worthwhile.

Recommended Directions for Informal Caregiver Solutions during COVID-19 and Beyond

Even prior to the pandemic, pressing caregiver needs have been largely overlooked among policy solutions and healthcare quality improvement efforts, amounting to a population of unpaid healthcare workers who are undervalued [9, 11]. Meanwhile, research suggests that lack of awareness of informal caregivers’ health literacy, disease knowledge, medical care ability, and financial stability challenges have limited the resources provided to those in need through policy measures [11]. Compounding the need for immediate solutions, the pandemic has not only increased the population of informal caregivers but also the burden and intensity of unpaid caregiving during a considerably stressful time [9, 11]. The most recent World Health Organization (WHO) guidelines for home caregiving policy were updated in March 2020 at the onset of the pandemic, primarily focusing on controlling the risk of COVID-19 spread and managing cases of infection at home, yet generally lacking other specific direction for providing informal care during the pandemic [11, 22]. Previously, the burden of unpaid caregiving, especially for aging adults, had shifted incrementally from the acute care setting to home over a period of many years [49, 50]. Now, the pandemic has accelerated this dynamic, with significantly strained acute care resources and workers necessitating the transfer of a widening population of patients to home care settings [49]. Healthcare priorities have focused on preventing virus spread in hospitals, long-term care settings, and communities; maintaining staffing to care for COVID-19 patients; and avoiding provider burnout; thus, caregiver support from formal healthcare systems has suffered [51].

Immediate solutions for caregiver burden remain limited, yet recommendations are emerging to provide direction for addressing these needs. The Embracing Carers Well-Being Index study findings revealed five key themes requiring attention during the COVID-19 crisis: 1) Rising Demands; 2) Changed Responsibilities; 3) Toll on Caregivers; 4) Inequities in Caregiving; and 5) Paths to Solutions [30]. The survey also elicited caregivers' perspectives on solutions they desire for improved support and relief. Notably, 94% of respondents agreed that employers need to provide additional flexibility for caregivers, with nearly 60% stating that their employers currently do not provide sufficient support for their caregiving roles at home [30]. These realizations strengthen views that private sector employers must provide better workplace flexibility, benefits, and financial resources, especially while many employees serve as informal caregivers for the duration of the pandemic [9]. New research from AARP also reveals the potential benefits of improved employer and government initiatives supporting family caregivers age 50+ during this time. Projections from “Caregiving in the US 2020” indicate that better support could boost the US economy by as much as $1.7 trillion by 2030, primarily through increased productivity in paid positions as well as reduced financial impact and personal costs among caregivers [52]. Meanwhile, 83% of caregivers also report feeling that the US government should provide greater support for COVID-era caregiving, a perspective aligning with expert recommendations that government agencies should continue to develop policies to support family caregiving [9, 30].

A large majority (94%) of informal caregivers feel that healthcare systems must provide more assistance; notably, 80% also express the need for greater support from insurance providers and organizations [30]. Research demonstrates a clear need for better training, education, and support in safety protocols, treatment techniques, infection control, and even medication management; thus, the role of healthcare providers remains critical for caregivers in the home setting [9]. Public health initiatives can contribute to this effort, through funding provided by the Coronavirus Preparedness and Response Supplemental Appropriations Act, passed in March 2020 [53]. Specifically, the bill allocates $1.9 billion for the Centers for Disease Control and Prevention (CDC) response to the pandemic, including both state and local efforts [53].

Furthermore, family physicians, primary care teams, nurses, or other community and social work professionals may be in a position to identify and assess caregiver needs and gaps in care, and subsequently refer them to necessary resources [2]. Also worthwhile is the consideration of caregivers' mental health needs, as well as assistance with navigating healthcare and insurance complexities [2]. Similarly, healthcare providers and leaders must serve as advocates for family caregivers, especially considering the extreme conditions of caregiving during a pandemic [38]. Recommendations in the literature have proposed addressing PPE needs; utilizing risk assessment questionnaires to assess capacity for providing intense care at home; formal training for safety protocols; and development of telehealth options to enable virtual visits [38, 49]. Consequently, for telehealth to become a true asset in caregiving, healthcare providers and insurers must adopt telemedicine options as an essential resource, with insurance plan coverage for virtual visits over the longer term [9].

Finally, agencies serving vulnerable older adults have made valuable contributions by implementing measures to identify caregivers with severe needs and provide connections to appropriate resources [54]. The US Department of Veterans Affairs has taken a leading role in this effort, by publishing guidelines for healthcare practices to support family caregivers during the COVID-19 crisis [54]. Examples of these guiding recommendations appear in Table 2. Overall, as our findings demonstrate, designed interventions to address informal caregiver burden during the ongoing pandemic remain limited, yet important recommendations for policy and healthcare planning directions have been proposed.

Table 2. Recommendations to Support Family Caregivers during COVID-19 [54]

Recommendation	Guidance for Healthcare Providers
Identify and Reach Out to Caregivers with High-Risk Patients	Develop a systematic identification and assessment approach Tailor outreach and interventions to the specific practice setting Use a team approach and involve staff members to coordinate care and be available to caregivers of high-risk patients
Screen for Loss of Home Support for Caregivers of Complex Care Patients	Assess caregivers for difficulty obtaining essential services and resources
Connect Caregivers of Complex Care Patients to Needed Resources	Connect caregivers to support networks, including home health agencies and counseling Stay updated on changes in community services
Provide Caregiver Education and Support	Develop list of local resources for caregivers Share links to COVID-19 resources, organizations, support groups Connect caregivers to local social workers and case managers
Use Technology for Support	Support caregivers through technological communications Supplement care with telephone/video/virtual contact Limit face-to-face visits as much as possible for safety precautions

Source: Dang S, Penney LS, Trivedi R, Noel PH, Pugh MJ, Finley E, et al. Caring for Caregivers During COVID-19. Journ of Amer Geriatrics Soc (JAGS). 2020;68(10):2197-2201.

Limitations

Our literature search spanned a relatively short time period, focusing on research published from early 2020 to early 2021 to align with the pandemic timeline. Larger studies over the longer term to evaluate shifting caregiver burden would bring additional insight to these findings. Furthermore, most studies examining informal caregiver burden during the pandemic were conducted typically for short periods of time with small sample sizes. Regarding study samples, most published research gathered information from a wide scope of ages, primarily from caregivers age 18 and older, rather than stratifying by useful age groups including older adults. Thus, drawing distinct conclusions on the impacts of the pandemic on caregiving at various ages and life stages was not possible. In addition, most relied on self-reported data, information that may vary or be influenced by the severe stress and emotional fluctuations of respondents due to the rigors of the pandemic. Lastly, published findings to date show only the immediate short-term impacts of COVID-19 on caregiving, rather than lasting implications for informal caregivers. However, the findings in this review provide a base of knowledge for important future research directions to identify and alleviate informal caregiver burden during times of crisis.

Conclusions

The onset of the COVID-19 pandemic triggered an unprecedented crisis for informal caregivers, as well as family members thrust into caregiving roles for the first time. As such, many informal caregivers have faced the reality of sudden, drastic changes to their own lives at a time when formal healthcare supports have diminished. Consequently, emerging research suggests that caregivers are experiencing severe burden and intensity due to their shifting roles, placing them at high risk for suboptimal health outcomes. Even prior to the pandemic, informal caregivers were often overlooked and inadequately supported as an essential piece of the US healthcare system. In the current crisis more than ever, immediate and innovative approaches to alleviate caregiver burden and provide ongoing support over time are long overdue.

Notably, the literature identified in this review did not highlight the potential benefits of caregiving, including a sense of purpose in life, greater resilience, and feelings of social connectedness between caregivers and their care recipients. Further work to identify the potential to utilize and rely upon these positive attributes of caregiving should become a priority.

Long-term impacts of the pandemic on informal caregiver burden remain unknown but will likely be significant and lasting. To that end, greater resources devoted to assessment and understanding of caregiver needs will help inform initiatives and policy directions for a better caregiving environment post-pandemic. Education, training, technological resources, financial support, and mental health initiatives to mediate caregiver burden during times of crisis and public health emergencies will be crucial for the well-being of informal caregivers far beyond the end of the pandemic era.

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