



# The Caregiver Intensity Index: A Novel Tool to Assess and Describe The Unpaid Family Caregiver Experience - Updated: July 2020

## Overview of The Caregiver Intensity Index

The Caregiver Intensity Index was developed to provide a broad understanding of the individual experience of caregiving: what hurts, what helps, and the toll it takes. The caregiver experience is not static nor is it limited to the type of care we give, where we provide it, and the ‘burden’ of doing so. We believe the caregiver reality is not only multi-dimensional, but that those dimensions include life factors that may contribute to or reflect family conflict, financial stress, and time constraints – as well as to buffers like feeling supported by others (home and work), feeling informed, and also finding meaning and satisfaction in caregiving. These life factors include the health of one’s relationships outside of caregiving, perceptions about the state of the country, and expectations for one’s financial health, (ideally) meaningful work, and personal health.

The Caregiver Intensity Index was created to support two use cases: 1) reflect an individual caregiver’s experience, and 2) give the systems designed to support caregivers sufficient granularity to do so effectively. Unpaid caregivers are the iceberg underlying and supporting healthcare, and yet society at large often requires caregivers to seek out support and misses the opportunity to anticipate their needs. We believe in flipping this reality – rather than requiring caregivers to ‘self-identify’ we envision a system that is purpose-designed to ‘see’ caregivers, even before they recognize themselves in that role. This proactive recognition is the first line of care.

The Caregiver Intensity Index – through *data and stories* -- creates the crosswalk from an individual caregiver’s experience to population insights that can support development of products, tactics, approaches, and solutions that reflect the complex caregiver reality. The Caregiver Intensity Index, in its applied form, is a web-based caregiver ‘quiz’ designed to engage caregivers, assess the intensity of and provide a ‘score’ in validation of their experience, and connect them to the resources of our sponsoring partners. In its research form (The Caregiver Intensity Index ‘Plus’), the instrument is fielded regularly, and its use expanded to build an evolving knowledge-base reflecting current events and changing caregiver dynamic

## Introduction

An estimated 53 Million adults provide unpaid care for a friend or family-member each year in the US<sup>1</sup>. The type, level and nature of care varies widely, from occasional social support to full-time support of daily medical, nutrition, and hygiene activities.

In many cases, those delivering care do so in isolation. Many do not recognize themselves as ‘caregivers’ and may not seek or have access to assistance in their caregiving responsibilities<sup>2</sup>. As a result, the burden, shame, and exhaustion of caregiving remains hidden. ARCHANGELS was founded to recognize caregivers, celebrate their contributions, and connect them to resources.



ARCHANGELS developed the Caregiver Intensity Index (CII) to help identify and quantify caregivers' strengths and needs for support across an array of caregiving domains. Many inventories measure caregiver intensity typically focus on the stressors that contribute to negative outcomes, such as using Instruments/Actions of Daily Living (IADLs)<sup>3,4</sup>. ARCHANGELS took a wider view, and conceptualized the buffers of caregiving that can mitigate these stressors. This novel framework also addresses lacking elements in other inventories, including the role of community and employment support in caregiver load<sup>5</sup>.

Additional research studied the connection between components of caregiving and known mental health challenges such as stress, depression, and anxiety.

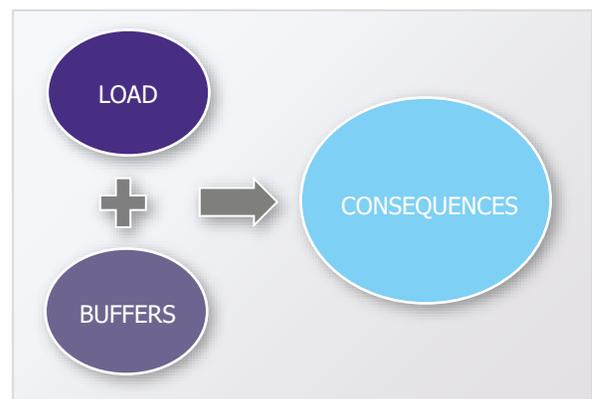
### **Development of The Caregiver Intensity Index (CII)**

In 2018, a quota sample of 1020 individuals was selected from a commercial survey sampling firm's standing panel of caregivers. Efforts were made to ensure the sample was broadly representative by geographic location and demographic characteristics, but given the focus on instrument development, representation of the variety of caregiver experiences was judged to be more important than geographic and demographic representativeness. Quotas were set for employment status, caregiving location (in or out of the respondent's home), hours of care provided, and tenure in the caregiving role. Eligibility criteria included being currently engaged as a caregiver and being 18 years of age or older.

Foundational development of The Caregiver Intensity Index (CII) included factor analysis of 108 items grouping them into twelve unique factors. Each of the factors was then grouped into one of three broad categories -- caregiving load (time, finances, family, self-doubt), caregiving buffers (access to needed information, self-confidence, meaning and purpose, and employer support) and caregiving outcomes (self-neglect, stress/depression, resentment, work productivity). To minimize respondent burden, a second round of analysis identified two to three items per factor that had the highest factor loadings.

### **Caregiving Framework**

While there are many ways to describe and categorize caregiving, the CII uses the following real-world framework. A person providing care will experience a series of personal challenges and deficits that contribute to the overall load of caregiving. Those challenges are balanced by positive experiences of learning, support and satisfaction associated with caregiving. The combination of load and buffers contribute to the consequences caregivers experience in their own health, life and work as a result of caregiving responsibilities. Each of these three aspects of the caregiving framework, and how they are measured by the CII are described below.





## Caregiving Load

Based on data from interviews and surveys of several thousand respondents, The Caregiver Intensity Index measures four domains of load typically experienced by caregivers.

1. **Time:** The time demands and unpredictability of caregiving responsibilities, can be disruptive. The following are excerpts from comments provided by caregivers in the factor analysis phase of CII development:

“I found that at this stage and where we are right now because of the **uncertainty**... the pattern of our **routine has been changed** and yet I am **not exactly sure** what it is changing into, and so I **have to wait**, but in the meantime... I don't know expect from **day to day**, so my life now is like, okay, I can have a plan, but that does not mean that that is the way it is going to work out. I tell everybody I am just **moment by moment**.”

“Well the evenings you know we had to put them to bed **every night**, put dad to bed and if they were like watching a movie, they wanted to finish it and my husband and I would sit at the table, he gets up at 5:15 to go to work and I am up at 6:45 and we are at 10 o'clock going, “okay they have only got a half an hour left,” so our **freedom** of what we wanted to do was **completely taken away**.”

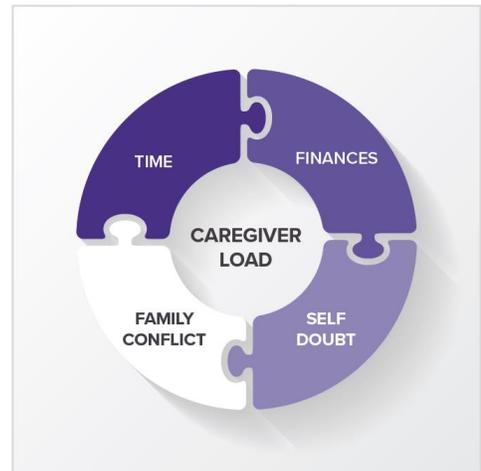
2. **Finances:** The expense of providing care and constraints that places on other financial needs contributes to caregiver load:

“Yeah, the **biggest stress** at that point was **financial** and dad's declining health. The **concerns** were, how are they going to fit into our lives with three teenagers in high school, one in middle school at the time making sure that they did not parent the kids was really **critical**.”

“The **financial piece** is that my husband and I were paying the largest portion of their rent ...so we had to move them out of their house ... I **could not afford to pay their rent** anymore”

“I have had to give up multiple job offers because of the hours. I regret doing this because those were high paying jobs.”

3. **Family:** Caregivers often face conflicts with family members who do not agree or contribute equally to care:





“...my **brothers do not truly realize what I have taken on**, well they say they do. Both of my brothers, I love them dearly, they have been very sweet, helpful, kind, generous, say, “Oh, well I would have taken them.”

“Yeah. It was **really hard on my family**. I think it was really hard on my husband who...you know my dad - he didn't have his own living space, so you know everything from what is on TV to what time we are eating dinner. I remember the first time I made him a meal and just put it on the table and said, “Here is dinner for you but we are rushing because some are getting home, and others are leaving and we have practices,” and he pushed it away and said “I don't eat alone,” and it was like “What, what do you mean you don't eat alone?” and he was furious that we weren't all going to sit down to the table and eat together and he wouldn't eat dinner and I said, “You know, I am going to be lucky if I can grab a hotdog at a ballpark.”

4. **Self-Doubt:** There are nagging doubts about being prepared and how best to handle care responsibilities.

“I definitely **thought that it would be easier**. He is not a lot of work. He does not make a mess. Very little laundry. I am already cooking dinner, all of that was not hard. It was the emotional piece. It was being his everything. I was prepared to give him a place to live and help him, but I wasn't prepared to be his best friend, his only friend.”

“Am I really a caregiver? He does not live in my house every day. He did and that was so hard that I couldn't stand him tapping his fingers on my kitchen table. For hours he would sit and just do this and do little patterns in his head and I was trying to work and write because I work at home on my computer and I would be like, “stop tapping your fingers.” So I feel kind of **guilty** because I know some people have it so much harder you know that they have to have their person in their house and this is going to be a huge issue because people are living longer and medicine is so good and it is tough.”

Each caregiver experiences a different combination of load variables. Overall, initial CII respondents reported experiencing all of these load variables to some degree, with time and family conflicts rating slightly more problematic than the others.

## Caregiving Buffers

Based on data collected during its development, The CII identifies four domains of buffers that buoy caregivers. These factors mitigate or lessen the negative effects of caregiver load:

1. **Being informed:** Caregivers feeling that they have the knowledge necessary to be successful providing necessary care was found to be a positive buffer.





“I think that is just the entire process because you are **figuring it out as you go along** and even though they are telling you what to expect like he is going to lose the mobility to walk or feed himself, you eventually learn all the tools and Hospice was helpful with that, but I think every step of the way is losing something and then **finding the information.**”

“Because I am kind of someone who will seek out and do things that are necessary, so I found them online, **I did some research**, I looked and weighed out you know what and because I had spent all of that time with him, I had become almost as **proficient** as the nurses and the doctors in what to do, what to say, what I needed and so it allowed me to be **far more able to navigate**, far better because I knew because I had been here months now.”

2. **Feeling Support/Self-Confidence:** One is feeling that they have the support of their close community.

“Listen, I take one day at a time. I am always an optimistic person. I usually approach every day with anticipation, none of it gets you down. You just do what you need to do and thank God you have the strength to be able to do it and the other part is you know when you **have been a part of a neighborhood** or have been as involved as I have been with a neighborhood, then there is always friends and those same neighbors and people that care about you still. They surround you.”

“I guess I get a sense of satisfaction in knowing that I am looking out for her and she is being well cared for and she is in the company of somebody who is doing something for her that is not going to harm her or take advantage of her. I get a sense of peace and solace and comfort and satisfaction from knowing that it is me and I am not going to do anything to hurt her. I am kind and thoughtful knowing who I am. I am just happy that I am able to do it.”

3. **Meaning and Purpose:** Caregivers may also gain a ‘lift’ from finding intrinsic fulfillment in the act of providing care.

“There is so much positive. The positive is that my kids got to spend a lot of time with their grandparents and they are all really, really close. My kids became very compassionate and have seen firsthand how you care for people and how you help no matter what. Even their friends at times, especially, my son, you know they were in a jam and my son was there and his friends were there, the friends would come and help care for him but it was a great lesson for the kids just teaching them how you treat people and it was also fun how they picked up things from my mother. She is a painter so she would paint with them or sew with them and do that sort of old fashion things and cook together. Our friend group embraced our parents as well. Our house became the hang-out house because we could not really go. It became our house and **everyone just embraced them.**”

“The most positive experience, it actually started when I was taking care of my mom, is you get to look into someone’s eyes who needs you like that and you can feel her soul. **You can feel just that they need you.** They appreciate you helping them be a dignified human and



then in my mom’s eyes I just saw such need. It was almost like a 3-year-old reaching up to be picked up, **kind of really just basic primitive need for love and care.** It just blew me away.”

4. **Employer/Work Support:** For those who are employed outside the home, feeling supported by their employer can be important.

“My brother and I take care of our mother. She lives at home with paid caregivers coming into the house, but there is not a moment during the day when we are not thinking about her. Our phones can ring at any time and I might need to step away from work to deal with something or even have to run to her house to check on her. I did not tell people at work about my mom’s health for a long time. Once I did it was really surprising how many people are in the same boat.”

Across caregivers surveyed in the CII, meaning and family/friend support were rated more strongly as buffers than information and work, although all were notable.

## Caregiving Consequences

Caregivers experience many consequences resulting from their responsibilities.

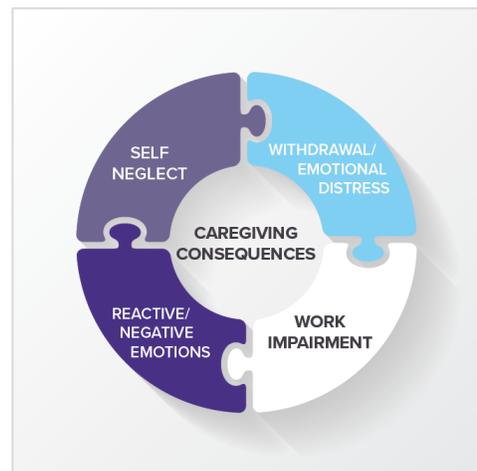
1. **Emotional Distress and Withdrawal:** Caregivers may also experience symptoms of depression, isolation, and emotional exhaustion.

“The most surprising thing was the isolation that I fell into, not by choice it just happened, that I wasn’t as available to do other things like go out with friends. Working had me out in the world and I loved it, I loved talking to people and I loved being useful and here I felt like I was starting to get really not useful, although my daughter keeps saying, ‘mom you are amazing, you are a saint... and I am like, yeah, that might be true but I don’t feel as useful. So what surprised me was all of a sudden **I felt like I was kind of sinking into a whole other life and I didn’t know it was going to feel like that.**”

2. **Work Impairment:** For those employed outside the home, caregivers report lower performance, lost earnings, or lost opportunities for advancement.

“I was working [and caregiving], and I was traveling and **I couldn’t take care of her and work.** So, the company said, ‘We’re gonna let you go.’ ... we had three houses and it, it was kind of a disaster. We lived all through it, we’re here. We’re okay.”

“Many millennials rely on gig-economy jobs like food delivery or rideshare services. Our baby boomer parents are getting older and many of them are getting sick. So for many millennials, we’ve found ourselves taking on caregiver responsibilities sooner than we expected, **on the**





heels of job uncertainty. I, for one, did not expect to be dealing with all of this at such a young age”

3. **Negative Reactive Emotions:** The demands of caregiving can also give rise to reactive emotions such as anger, resentment, and guilt.

“I have all the tools that I need to take care of her. I have the time, she has the money for whatever she needs. **I guess I just wish other people in her family showed that they cared as much about her** as I have come to care.”

“Many feelings come up when you are caring for someone day in and day out. Many caregivers set out saying, "This won't happen to me. I love my mother, father, husband, wife, sister, brother, friend, etc." But after a while, **the "negative" emotions that we tend to want to bury or pretend we aren't feeling come up.** Caregivers are often reluctant to express these negative feelings for fear they will be judged by others (or judge themselves) or don't want to burden others with their problems.”

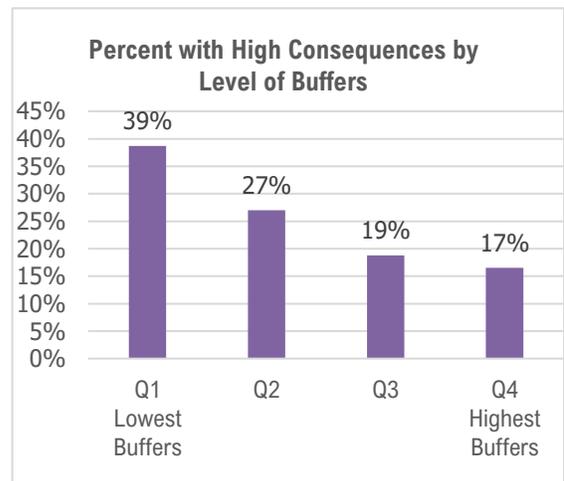
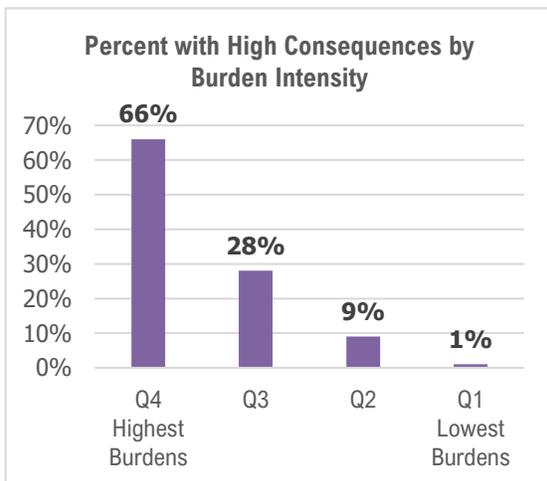
4. **Self-Neglect:** Frequently, caregivers report neglecting their own personal and social needs.

“**Oh, I don't sleep at all.** Look at the circles under my eyes. Well, when you have a kid who has seizures...you don't sleep and when you have a husband that snores, you don't sleep and then when you are in the middle of that and trying to listen to see if your mother needs help in the middle of the night you don't sleep.”

Across initial CII respondents, all consequences were reported to some degree, with emotional distress and self-neglect rated slightly stronger than the other impacts.

### Combined Framework

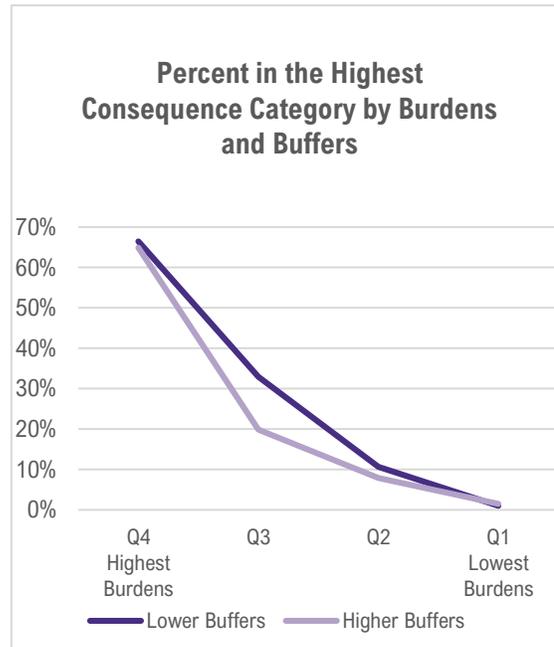
Based on responses from over 1000 caregivers, the CII framework confirms that greater load correlates with higher levels of negative consequences (defined as being in the top quartile).





Conversely, greater buffers correlate with lower levels of negative consequences. While both matter, as seen in the figures, reported load intensity has a larger overall impact on consequences, where 66% of those with the highest load intensity (defined as the top quartile) have high consequences (defined as the top quartile) compared to only 1% of those with the lowest load intensity. The range of high consequences across buffers is only 36% (of those with lowest buffers) to 17% (of those with highest buffers).

Considered together, having more buffers (support, information, meaning) does decrease the degree of negative consequences (self-neglect, distress, and negative emotions) of load intensity. However, it appears that buffers help to mitigate the effects of burdens most at middle-levels of load intensity. This suggests that people facing the worst load intensity (time, finances, self-doubt, family conflict) may need help reducing that intensity first.



The 12 subscales have very strong internal consistency reliability, ranging from  $\alpha=0.72$  to  $\alpha=0.89$ . The overall 26 item CII measure had an alpha of 0.91. The inclusion of caregiver interviews and a comprehensive literature review of caregiving instruments during the development process helped ensure that the items tested for the CII had strong face validity.

### Mental Health and Caregiving Intensity

Caregiving can take a toll on mental health. Studies have shown a connection between the intensity of caregiving burdens and the likelihood of caregiver mental health problems<sup>6,7</sup>. Not surprisingly, the CII shows the same relationship.

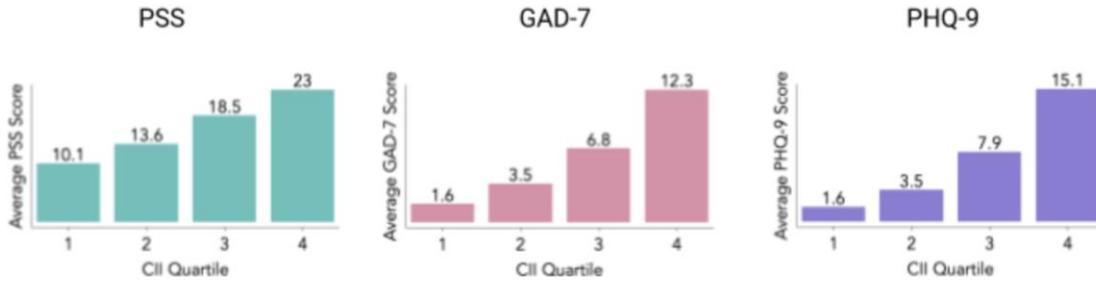
### Psychometric Properties

Criterion validity was tested by comparing responses on the CII to responses on three standard measures of psychological well-being, the Perceived Stress Scale (PSS), the Patient Health Questionnaire 9-item depression screening scale (PHQ-9), and the Generalized Anxiety Disorder 7-item (GAD-7) instrument<sup>8,9,10</sup>. Correlations between the CII and each of these three measures were strong, positive and in the expected direction (Table 1).

Table 1: Correlations Between CII and Psychological Outcomes

	CII	PHQ-9	GAD-7
PHQ-9	0.726		
GAD-7	0.692	0.839	
PSS	0.688	0.681	0.715

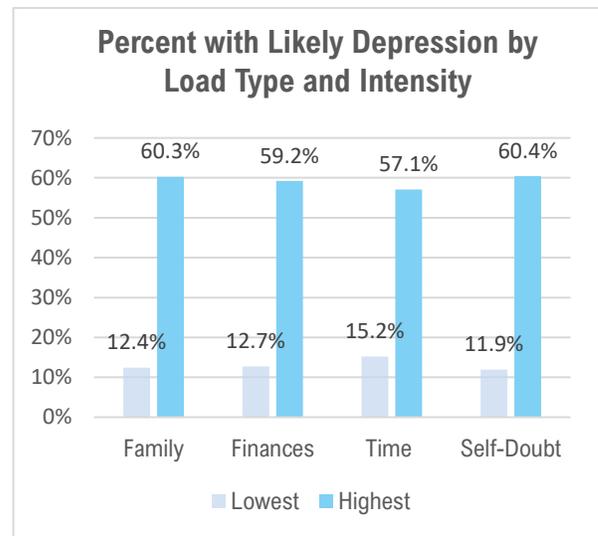
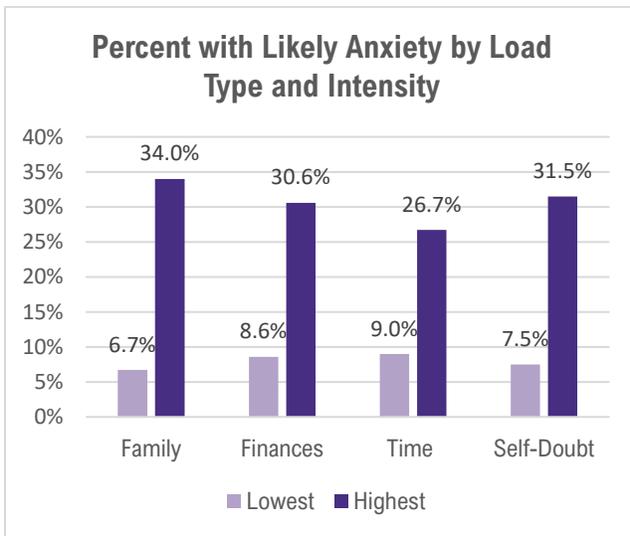
The CII is intended for real-world application to identify and quantify the challenges and needs experienced by caregivers.



All inter-quartile differences were statistically significant via one way ANOVA with  $p < 0.0001$

For all three outcomes, progressively higher CII scores correspond to increasingly concerning levels of stress, anxiety and depression. In the case of anxiety and depression, average scores for those in the highest quartile of CII indicate a high likelihood of clinical illness (scores above 10). Stress levels are also high, with 75% of caregivers (those in top three quartiles of CII) exceeding the national average score of 13.

Looking more specifically at the sources of caregiving load, it is evident that all four of the load subscales measured in the CII contribute to mental health issues.



Those rating any of the four loads highest (top quartile) have a three-to-five times the likelihood of clinical anxiety than those rating burdens lowest. Similarly, those reporting highest load have a four-to-five-fold likelihood of clinical depression. Caregivers reporting a high level of family conflict or a high level of doubt and uncertainty were especially prone to signs of clinical depression or anxiety.



## Summary

The challenges of caregiving are diverse and result in many detrimental consequences. Caregivers report a variety of significant challenges, including family conflict, financial stress, and time constraints. They also report some “buffers” to the stress of caregiving, including support from others (home and work), becoming more informed and also finding meaning and satisfaction in their caregiving responsibilities. A high number of load items, combined with few buffers result in negative outcomes including neglecting personal needs, declines in work performance and emotional distress. Further, reports of greater load result in increased stress and likelihood of depression and anxiety.

## References

1. AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>
2. O'Connor DL. Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*. 2007;21(2):165-174. doi:[10.1016/j.jaging.2006.06.002](https://doi.org/10.1016/j.jaging.2006.06.002)
3. Fredman L, Doros G, Ensrud KE, Hochberg MC, Cauley JA. Caregiving intensity and change in physical functioning over a 2-year period: results of the caregiver-study of osteoporotic fractures. *Am J Epidemiol*. 2009;170(2):203-210. doi:[10.1093/aje/kwp102](https://doi.org/10.1093/aje/kwp102)
4. Vukicevic M, Heraghty J, Cummins R, Gopinath B, Mitchell P. Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration. *Eye*. 2016;30(3):413-421. doi:[10.1038/eye.2015.235](https://doi.org/10.1038/eye.2015.235)
5. Roach MJ, Welch L. Caregiver Well-Being - Toolkit - Brown University. Published September 2000. Accessed July 17, 2020. <http://www.chcr.brown.edu/PCOC/familyburden.htm>
6. Sallim AB, Sayampanathan A, Cuttilan, Chun-Man Ho R. Prevalence of Mental Health Disorders Among Caregivers of Patients With Alzheimer Disease. 2015. *Journal of the American Medical Directors Association*, ISSN: 1538-9375, Vol: 16, Issue: 12, Page: 1034-41
7. Kumagai N. Distinct impacts of high intensity caregiving on caregivers' mental health and continuation of caregiving. *Health Econ Rev*. 2017;7(1):15. doi:10.1186/s13561-017-0151-9
8. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613. doi:[10.1046/j.1525-1497.2001.016009606.x](https://doi.org/10.1046/j.1525-1497.2001.016009606.x)
9. Rutter LA, Brown TA. Psychometric Properties of the Generalized Anxiety Disorder Scale-7 (GAD-7) in Outpatients with Anxiety and Mood Disorders. *J Psychopathol Behav Assess*. 2017;39(1):140-146. doi:[10.1007/s10862-016-9571-9](https://doi.org/10.1007/s10862-016-9571-9)
10. Cohen, S. and Williamson, G. Perceived Stress in a Probability Sample of the United States. Spacapan, S. and Oskamp, S. (Eds.) *The Social Psychology of Health*. Newbury Park, CA: Sage, 1988