

**INDUSTRY PERSPECTIVES:**

# Engaging, equipping and supporting caregivers



**Industry perspectives:**

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## Executive summary

Caring for the elderly or those with chronic or disabling health conditions is no easy task, and it can be even tougher for those unpaid friends and family members who care for their loved ones on top of managing full- or part-time jobs, or who have been forced to stop working to provide care. Many caregivers juggle several aspects of their patients' healthcare beyond day-to-day needs, including coordinating appointments, monitoring symptoms, participating in doctor discussions, and in some cases, even making treatment decisions.

Pharma companies have increasingly recognized caregivers as crucial stakeholders and partners in care, and some, including Novartis and Bristol Myers Squibb, have built out caregiver-support programs. But research shows that despite these efforts, many caregivers are physically, financially and emotionally drained and don't feel equipped or qualified to provide optimal care.

Based on survey responses gathered in Fall 2021 from more than 2,000 caregivers, this report will explore caregivers' unique needs and what pharma marketers can do to help meet them.



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## Introduction

Caregivers provide an estimated \$500 billion worth of free care annually in the U.S., and that figure is projected to swell as the number of caregivers nationwide increases. As of last year, nearly 1 in 5 (19%) Americans were providing unpaid care to an adult with health or functional needs, according to the National Alliance for Caregiving and AARP, and the number of caregivers in 2020 jumped to 53 million, up from 43.5 million five years prior<sup>2</sup>.

As caregiving expands across the country, the job also is becoming increasingly difficult. Slightly more than 25% of family caregivers reported difficulty in coordinating care in 2020, up from 17% in 2015. And the number of Americans caring for more than one person also grew, hitting 24% in 2020, up from 18% in 2015.

As a result, more caregivers are experiencing problems with their own health, with 21% ranking it as fair to poor in 2020. Mental health is suffering, too, and the COVID-19 pandemic hasn't helped: 68% of caregivers surveyed by Merck KGaA in 2020 said the pandemic had worsened their emotional and mental health, with nearly one-third of that group saying that they didn't feel they had anyone to turn to for support<sup>3</sup>.

That's not only a problem for caregivers, but for the patients in their care, too—and to successfully help those patients, the pharmaceutical industry will have to make sure that caregivers are getting the support they need.

So what exactly can pharma do? Phreesia Life Sciences set out to answer that question in September and October 2021 with a nationwide survey of 2,084 caregivers who were checking in for doctors' appointments, either for themselves or for their patients.

The survey captured responses from both paid and unpaid caregivers, with 76% identifying as female and 56% reporting their age as 55 or older. Survey respondents care for patients across age ranges with a variety of health problems, including dementia (23%), heart conditions (18%) and mental health conditions (15%).

## Engaging caregivers

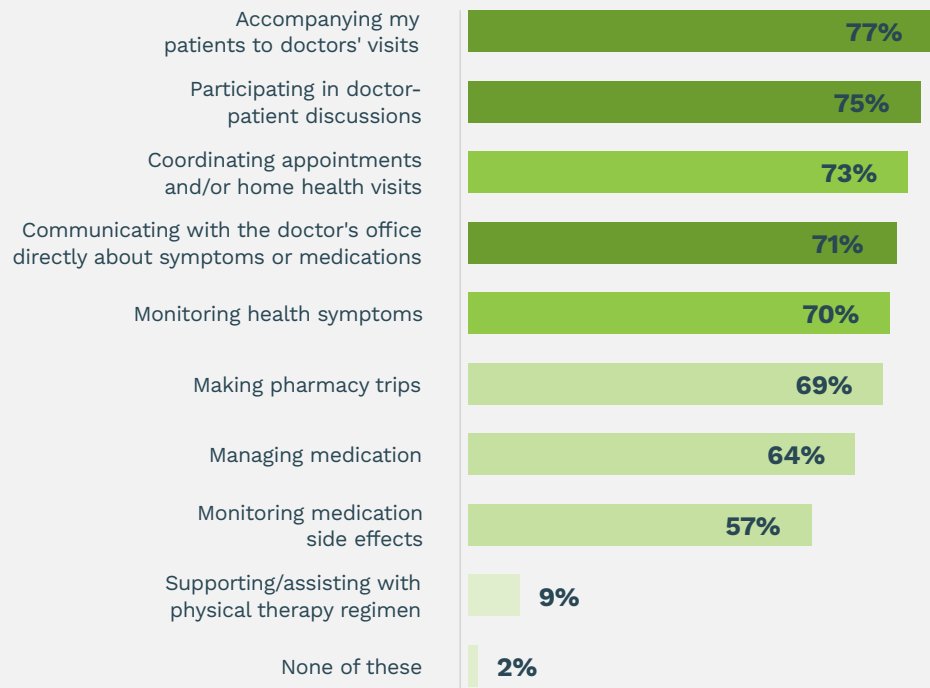
Caregivers are deeply involved in multiple key facets of their patients' care, and almost all of them are responsible for healthcare-related tasks that range from making pharmacy trips to managing medication side effects. Among surveyed caregivers, top duties included communicating with their patients' healthcare teams, coordinating appointments, monitoring their patients' health symptoms, and managing aspects of their patients' medications.

Additionally, when caregivers communicate with their patients' healthcare teams, they tend to take the lead. More than 9 in 10 surveyed caregivers (92%) either spearhead or play an active role in their patients' conversations with their doctors, and the vast majority (87%) are involved in provider discussions about their patients' conditions or treatments all or most of the time.

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### Which of the following healthcare tasks are you responsible for?



n=2,056

Perhaps the most significant finding for pharma marketers is that caregivers frequently determine their patients' course of treatment. In fact, 52% of patients rely on their caregivers to make healthcare decisions for them, and another 30% always discuss their treatment plans or options with their caregivers before making healthcare decisions.

With so many caregivers serving as the primary decision-makers for their patients, it's critical that pharma marketers engage caregivers directly and tailor media to their experience. The industry's current messaging and imagery focuses on patients and the patient experience, but drugmakers may find more success—particularly in therapeutic categories where patients rely heavily on caregivers—if they can show caregivers that they understand their unique needs and can provide solutions that both help their patients and ease their own burdens.

### What role do you typically play in these doctor-patient discussions?



n=2,393

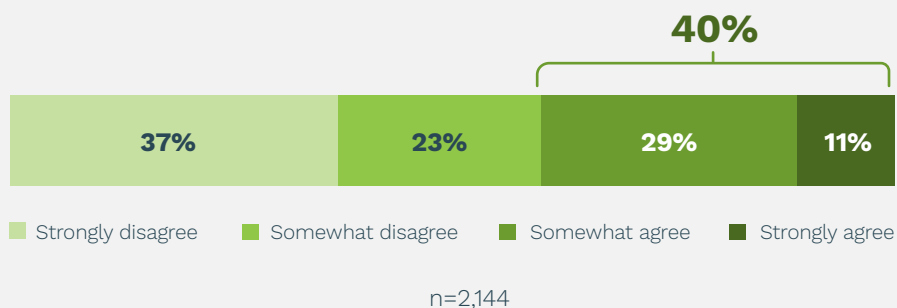
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## Equipping caregivers

Without any formal training, caregivers also often feel unprepared for the job. Indeed, 2 in 5 caregivers (40%) say they're not equipped with enough resources to provide optimal care for their patients, a conviction that's more prevalent among unpaid caregivers. On the flip side, only 37% of caregivers strongly believe they have the necessary tools to provide optimal care.

I do not feel that I am equipped with enough resources and tools to provide optimal care for the person I care for.



Those figures are especially significant considering that most surveyed caregivers weren't new to their roles: 65% had been taking care of their patients for three years or more, and 35% had been doing so for more than seven years.

To arm themselves with the information they need, caregivers frequently search online, with 73% heading to the web for health-condition-specific information at least once a month, and 20% searching online a few times a week. Those who care for patients with conditions such as Alzheimer's disease are even more likely to consult the internet: 63% of caregivers for patients with Alzheimer's disease conduct research on the condition several times a month.

To further complicate matters, when caregivers do go hunting for health-condition information, they often have to piece it together from multiple sources. More than half of caregivers (57%) use a patient portal to gather information or communicate with healthcare providers, but only 17% have their own log-ins to access those portals. Beyond portals and internet searches, caregivers typically turn directly to doctors (53%), doctors' office staff (43%), medication websites (33%) and friends and family (31%) to seek out information that will help them provide better care.

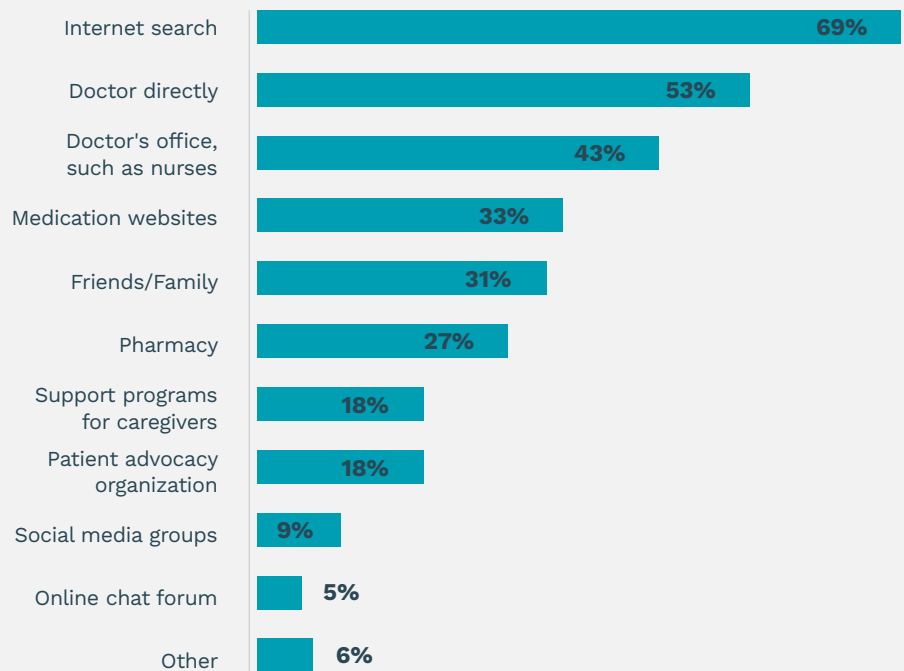


**65% [of caregivers]** had been taking care of their patients for three years or more, and **35%** had been doing so for more than seven years.

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## Where do you typically go to look for additional information to provide better care?



n=1,883

At a minimum, drugmakers can make these searches significantly easier for overburdened caregivers by streamlining and centralizing caregiver-specific information on their websites. But there's room for life sciences companies to go a step further by creating caregiver-specific information hubs and developing dedicated caregiver trainings and educational programs.

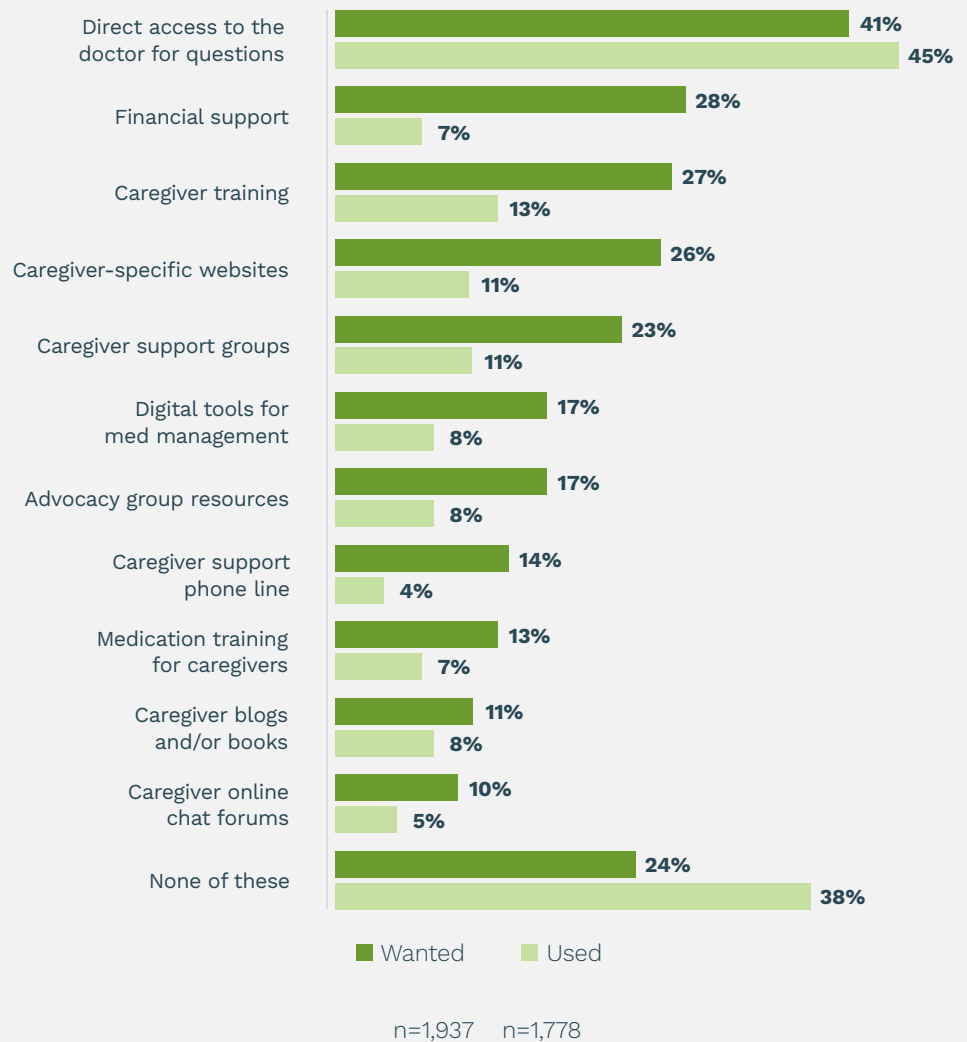
The demand is there: When asked what type of support was most important to them, 54% of caregivers requested education or training to help manage their patients' conditions. And having direct access to doctors to answer their questions is caregivers' top-requested and top-used resource, at 41% and 45%, respectively.



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Which of the following types of resources designed specifically for caregivers have you used/do you want?



That's not to say that pharma companies don't already make some of these resources available to caregivers. Patient support programs often include medication information and nurse hotlines, and some drugmakers already offer caregiver-specific support programs.

The problem is that caregivers don't necessarily know about these programs. The overwhelming majority—86%—have never used a patient-support program while providing care, and just 2% have ever used a support program designed specifically for caregivers. Drugmakers have an opportunity to not only help caregivers, but also to maximize their investment in them by expanding awareness of the resources they offer and making sure that those resources and tools get to those who need them.



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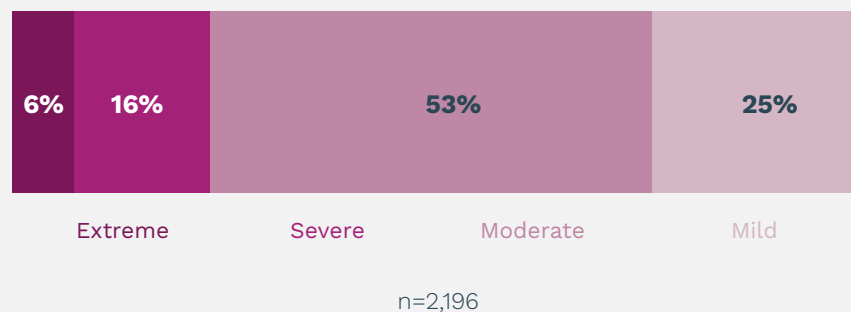
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## Supporting caregivers

On top of struggling to provide top-notch care, caregivers also grapple with physical, emotional and financial stress that can take a serious toll on their own health and well-being. A majority of caregivers (75%) reported moderate-to-extreme stress related to their caregiving duties, and 66% agreed that they prioritize the health of their patients over their own health. The problem is even worse among women, who are 1.2x more likely to report feeling stressed than their male counterparts and more likely to prioritize their patient's health over their own.

It's certainly no surprise that caregivers feel stressed, considering that many of them spend long hours on the job—often unpaid—for years at a time. Some 9 in 10 people who care for a patient with a chronic condition are unpaid, and more than half—54%—don't have another job outside of caregiving, in some cases because they've been forced to stop working to provide care.

How would you rate your level of stress related to caregiving?



Overall, 60% of surveyed caregivers spend more than 20 hours per week helping their patients. Among them, 37% also juggle a full-time job, and 11% have a part-time position. Unpaid Black caregivers are significantly more likely (58%) than unpaid white caregivers (44%) to have a job in addition to providing care. And 41% of all survey respondents reported spending more than 40 hours per week caring for their patients.

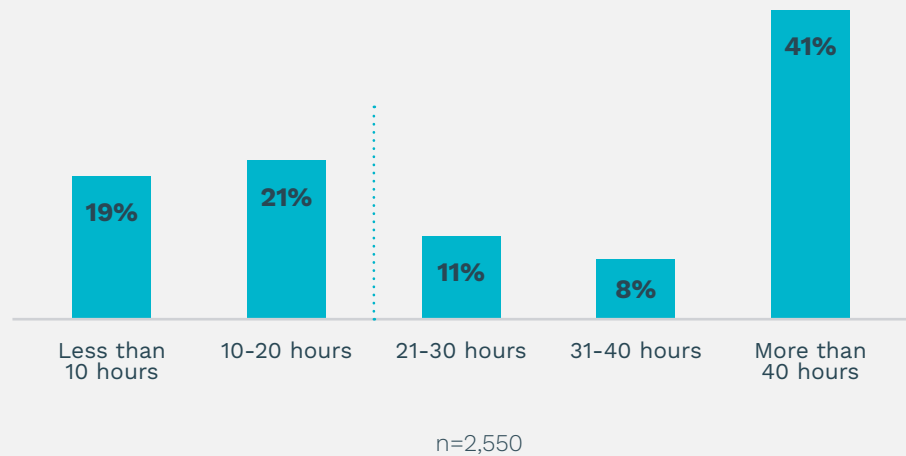
If pharma companies truly want to support caregivers, they need to go beyond education and find ways to ease their stress levels and financial burdens. Some 55% of caregivers rated emotional support—including stress relief—as their most important need, ranking it higher than education and training. Financial support was their second most-requested resource, with 28% of caregivers reporting that they wanted financial help, but only 7% reporting that they had received it.

Drugmakers can further address caregivers' unique needs by offering support groups, support phone lines and online chat forums where caregivers can connect with each another.

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How many hours per week do you spend taking care of the patient?



## Recommendations for drugmakers:

- ✔ Prioritize engaging caregivers directly since many of them are the primary healthcare decision-makers for the patients in their care
- ✔ Tailor messaging and imagery to demonstrate an understanding of caregivers' unique needs and highlight solutions that can help both them and their patients
- ✔ Build caregiver sections on patient websites or invest in caregiver-specific websites for both branded and disease-awareness campaigns to better meet caregivers' needs
- ✔ Create caregiver-specific trainings and programs that help them feel more secure in their roles and better able to provide optimal care
- ✔ Streamline and centralize existing educational tools related to health conditions and/or medications and post them where caregivers already search for information
- ✔ Develop support resources to help overwhelmed caregivers manage their stress, including support groups, dedicated phone lines and online chat forums
- ✔ Provide financial relief for caregivers
- ✔ Expand awareness of existing caregiver-support resources through omnichannel promotion

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## About Phreesia Life Sciences

Phreesia empowers life sciences companies to connect meaningfully with clinically relevant patients, delivering targeted health content in a one-to-one setting. Our PatientConnect offering identifies and motivates the right patients to initiate meaningful brand conversations, and our PatientInsights product enables our clients to better understand their target patient populations.

Phreesia meets patients where they are, both virtually and in-person, and reaches them at multiple touchpoints throughout their healthcare journey.

**To learn more about Phreesia Life Sciences, visit [lifesciences.phreesia.com](https://lifesciences.phreesia.com)**

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### End notes

1. ["America Is Running Out of Family Caregivers, Just When It Needs Them Most."](#) The Wall Street Journal, July 20, 2018
2. [Caregiving in the U.S. 2020](#), AARP and the National Alliance for Caregiving, May 14, 2020
3. The U.S. [Carer Well-Being Index](#), Embracing Carers®, Merck KGaA, February 2021