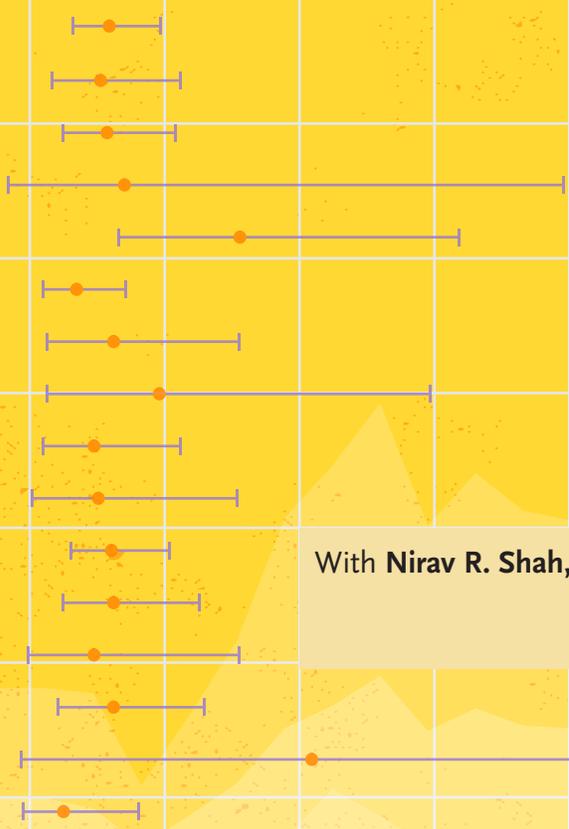




## How Health Systems Can Care for Caregivers



With Nirav R. Shah, MD, MPH, and Alexandra Drane

# How Health Systems Can Care for Caregivers



With Nirav R. Shah, MD, MPH, Senior Scholar, Stanford University School of Medicine, Clinical Excellence Research Center, Stanford, California, USA;  
Chief Medical Officer, Sharecare Inc., Atlanta, Georgia, USA



Alexandra Drane, Co-founder and CEO, ARCHANGELS and Rebel Health

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NEJM Catalyst Insights Council members say unpaid caregivers should be treated as part of the care team, but often are not.

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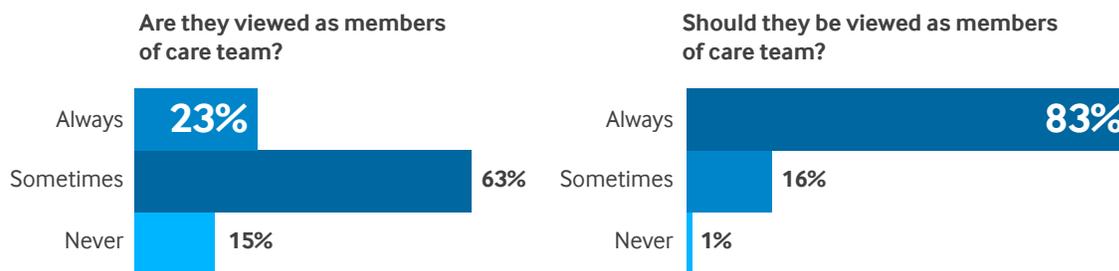
The Covid-19 pandemic exposed a fracture in the health system that has been bearing increasingly more weight: the stress of the unpaid caregiver. Shorter hospital stays, a transfer to more at-home services, and the fear of patient exposure to infection have all increased the load on family members, friends, and neighbors willing to care for patients.

“We’re creating these burdens without thinking of the consequences and what it means for people who have to take off work, who are not ready, or who don’t even necessarily want the caregiver job,” says Nirav R. Shah, MD, MPH, Senior Scholar at Stanford University’s Clinical Excellence Research Center and Chief Medical Officer of Sharecare. “With all we ask of unpaid caregivers, we haven’t even figured out how to address their needs or incorporate them into the care team.”

In a recent NEJM Catalyst Insights Council survey, only 23% of respondents say they consider unpaid caregivers part of the care team, yet 83% say they should be. The Insights Council is a qualified group of executives, clinical leaders, and clinicians at organizations worldwide who are directly involved in health care delivery. Unpaid caregivers are defined as any family member, partner, friend, or neighbor who has a significant personal relationship with an adult and provides that person with any form of assistance and care, such as helping with health care tasks and personal needs.

“The biggest untapped opportunities for health system administrators and clinical teams to impact the health and wellness of their patients — and to truly get to patient-centered care — is to care about unpaid caregivers,” Shah says, noting that unpaid caregivers in the United States avoid direct health care costs equaling as much as 2.5% of GDP. The NEJM Catalyst survey finds that

Should they be viewed as members of the care team ?



Base: 386

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the benefits of meeting unpaid caregiver needs are plentiful, including improved patient outcomes (selected by 72% of respondents), improved patient and family experience (68%), and improved treatment adherence (48%).

On the whole, survey respondents don't have strong initiatives to address unpaid caregiver needs. Just under 50% offer care coordination/navigation assistance, although 55% believe this to be one of the most useful initiatives for unpaid caregivers. Other initiatives score much lower, including support programs for employees who are also unpaid caregivers (29%), awareness campaigns (28%), and education programs to assist unpaid caregivers in their tasks (24%).

So what's keeping health care organizations from providing support to unpaid caregivers? According to respondents, the top barriers are insufficient staff support (e.g., social workers) (52%), lack of organization-wide strategic commitment (44%), and physician time limitations during clinical encounters (37%).

“ *The biggest untapped opportunities for health system administrators and clinical teams to impact the health and wellness of their patients — and to truly get to patient-centered care — is to care about unpaid caregivers.* ”

The survey also suggests that the health care industry is contributing to unpaid caregiver stress, says Alexandra Drane, co-founder and CEO of ARCHANGELS, a platform helping connect caregivers with resources. “Respondents say that care coordination and navigation assistance initiatives are their top and most useful resources — but they also understand that care navigation is overly complex and recognize there is limited coordination with social services and community-based organizations. This disconnect is often piled atop the financial, workplace, and relationship stress that caregivers are under.”

Covid-19 has further exacerbated caregiver stress. Sixty percent of respondents say mental and behavioral health issues have been significantly impacted by the pandemic.

“Caregiver intensity is real. But there are ways to help,” Drane says. A study by her organization finds that caregivers who report having even just one person supporting them have 40% less risk of depression and 30% less risk of anxiety. Caregivers who know respite services exist for them, even if they don’t use them, experience 70% less stress. She says it is imperative for health care organizations to not just alleviate the complexity and stress passed on to unpaid caregivers, but to help make sure caregivers realize the complexities of their role and that resources exist to help.

“Most caregivers don’t think of themselves that way. In their minds they’re ‘just a son, just a wife, just a neighbor,’” Drane says. “Providers can help remove the confusion (and even stigma) by making a caregiver question part of a regular office exam.” Just as important is how that question is asked: “Instead of directly asking if someone is a caregiver and do they need support, ask if they could easily go away for two weeks. That might start a conversation about how they can’t because they bring food every day to a sick aunt.”

Shah, who co-authored a recent article in *NEJM Catalyst Innovations in Care Delivery* on caring for caregivers, advises health systems to integrate caregivers deep into their processes. “Take your existing programs that you would offer to a patient and extend them to the caregiver as well,” he says, pointing to programs to address food insecurity, financial hardship, transportation, and the like.

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“*Remember, when the caregiver gives up, the patient ends up back in the ER and you get the readmissions.*”

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He also would like to see hospitals call caregivers post-discharge, not just patients, and to add more milestones such as a call three days out from discharge. “Everything is great for the first 24 hours — it’s after that when the patient and caregiver need help,” he says. “Remember, when the caregiver gives up, the patient ends up back in the ER and you get the readmissions. If you want to reduce readmissions, you might want to target resources to caregivers.”

None of these actions are easy and will certainly require resources, Shah says, but they are necessary if health care systems plan to rely even more on unpaid caregivers in the future. “There are many discussions about shortening hospital stays and ‘hospital at home’ right now,” he says, “but the truth is that health systems aren’t yet doing enough to help unpaid caregivers make this an acceptable reality.”

## Charts and Commentary

NEJM Catalyst surveyed health care executives, clinical leaders, and clinicians about caring for caregivers. Specifically, NEJM Catalyst Insights Council members were asked about initiatives in place to address unpaid caregiver needs, the most useful initiatives to support unpaid caregivers, technologies used to communicate with unpaid caregivers, familiarity with the CARE Act of 2014 and CARE Act practices currently used at health care organizations, barriers to addressing unpaid caregiver needs and providing support, benefits to health care organizations for meeting unpaid caregiver needs, whether unpaid caregivers are viewed as part of the care team, the extent of unpaid caregiver mental and behavioral issues and the impact of Covid-19, and ways in which the health care industry contributes to unpaid caregiver stress. A total of 386 completed surveys are included in the analysis for the March 2021 study.

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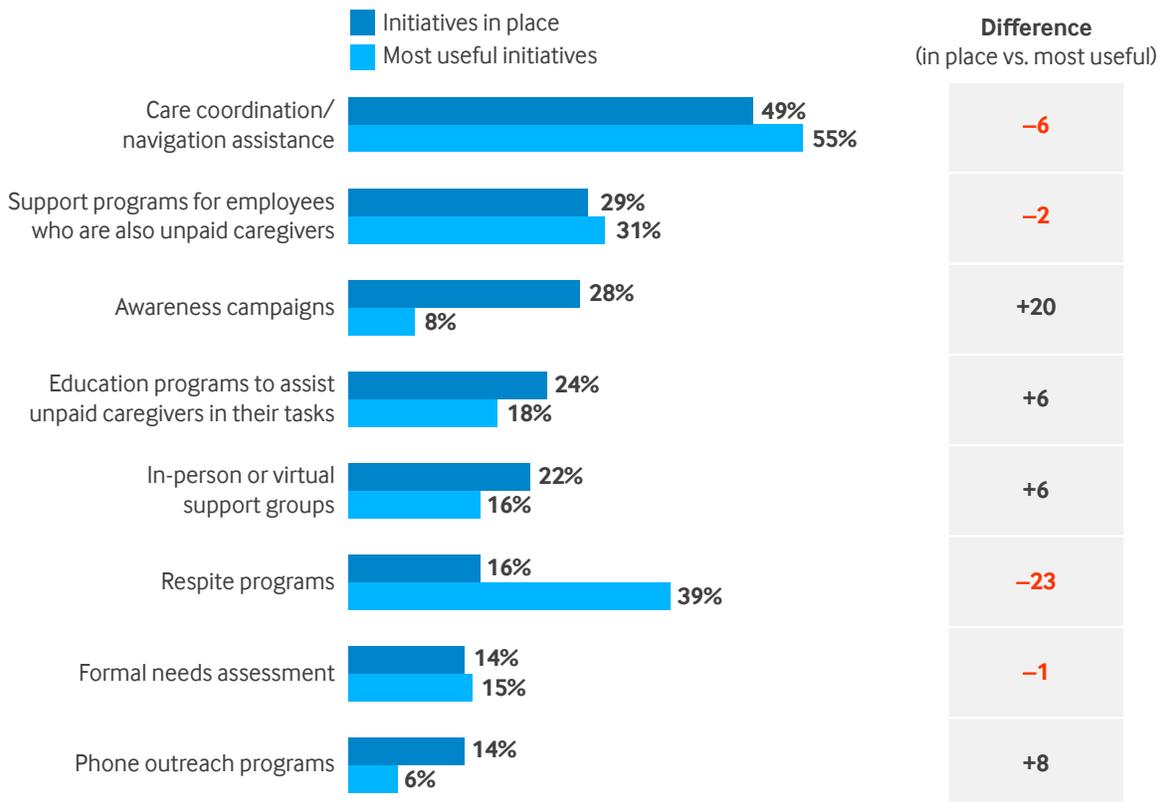
“ *Most caregivers don't think of themselves that way. In their minds they're 'just a son, just a wife, just a neighbor,' Drane says. Providers can help remove the confusion (and even stigma) by making a caregiver question part of a regular office exam. Just as important is how that question is asked: Instead of directly asking if someone is a caregiver and do they need support, ask if they could easily go away for two weeks. That might start a conversation about how they can't because they bring food every day to a sick aunt.*

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## Alignment and Gaps in Initiatives to Address Unpaid Caregiver Needs

Which of the following initiatives does your organization have in place to address unpaid caregiver needs?

What are the top two initiatives that are most useful for supporting unpaid caregivers?



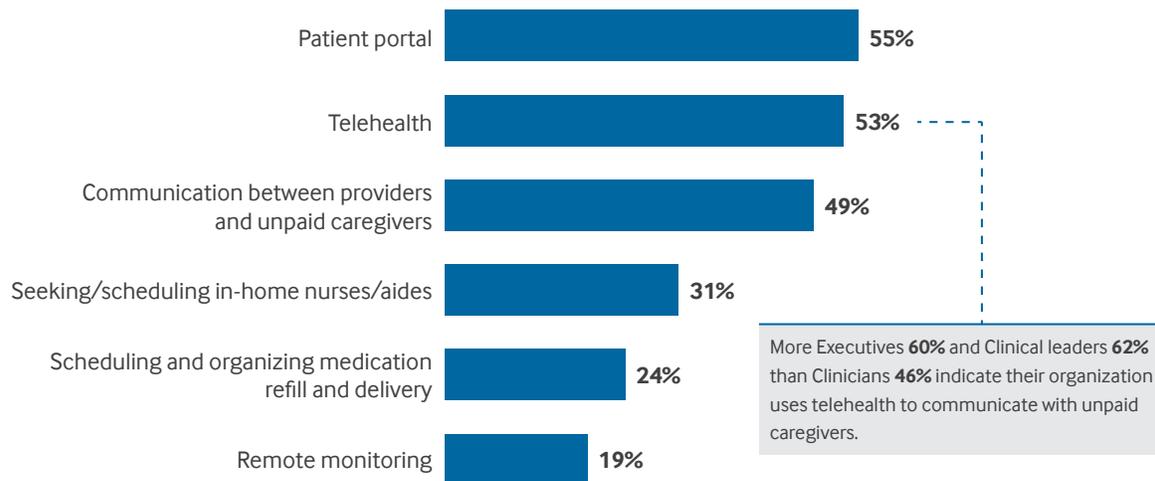
Base: 386 (multiple responses)

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The initiatives that health care organizations have in place to help unpaid caregivers line up, for the most part, with the initiatives that survey respondents consider useful — with two exceptions. Awareness campaigns are the third most frequently offered initiative, but only 8% of respondents list them as useful. Respite programs, on the other hand, are the second most useful initiative, but only 16% of respondents’ organizations offer them. In a written response, one clinician comments that health providers should support unpaid caregivers with “care coordination among all involved in a patient’s needs 24 hours a day.”

## A Range of Technologies Used to Communicate with Unpaid Caregivers

Which of the following health care technologies does your organization use to communicate with unpaid caregivers?



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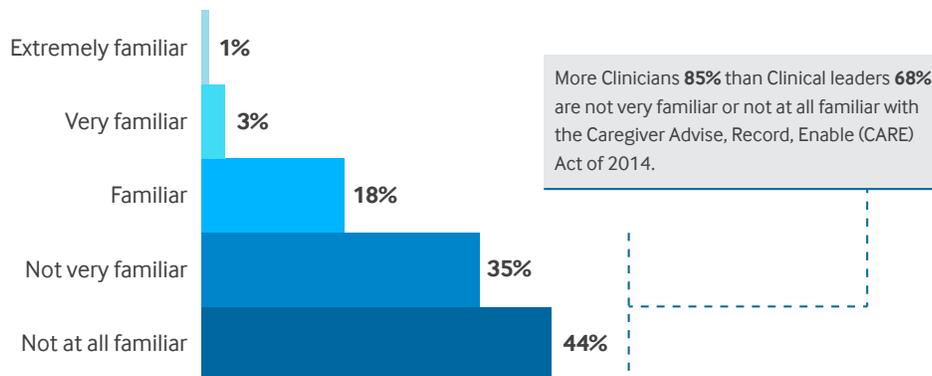
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Executives (60%) and clinical leaders (62%) are more likely than clinicians (46%) to indicate that their organization uses telehealth to communicate with unpaid caregivers. The need for communication is a common theme in written responses from respondents. One executive stresses that “communication must be specific to each patient, not some tear sheet about all abdominal wounds, or whatever.”

“*Take your existing programs that you would offer to a patient and extend them to the caregiver as well.*”

## Little Awareness of Law for Caregivers

How familiar are you with the Caregiver Advise, Record, Enable (CARE) Act of 2014?



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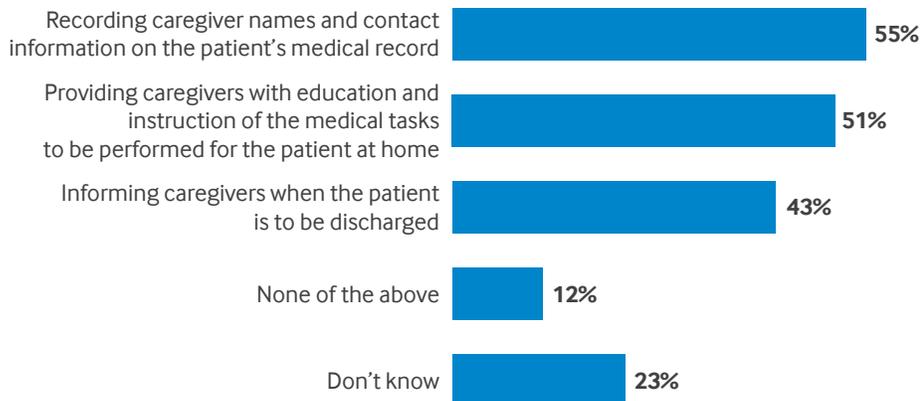
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A full 79% of respondents are either not very familiar or not at all familiar with the Caregiver Advise, Record, Enable Act (CARE), which has been enacted by 40 U.S. states, the District of Columbia, and Puerto Rico. More clinicians (85%) than clinical leaders (68%) are either not very familiar or not at all familiar with this statute. One clinician says it is imperative that providers “get to know which patients have unpaid caregivers, talk to those caregivers, and ask them what they need in the way of support, assistance, or help.”

“*It is imperative that providers get to know which patients have unpaid caregivers, talk to those caregivers, and ask them what they need in the way of support, assistance, or help.*”

## Moderate CARE Act Practices

Which CARE Act practices does your organization currently engage in?



Base: 386 (multiple responses)

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Even though most respondents say they are unfamiliar with the CARE Act, more than half do engage in two of the act's three practices: recording caregiver names and contact information on the patient's medical record (55%) and providing caregiver with education and instruction on the medical tasks to be performed for the patient at home (51%).

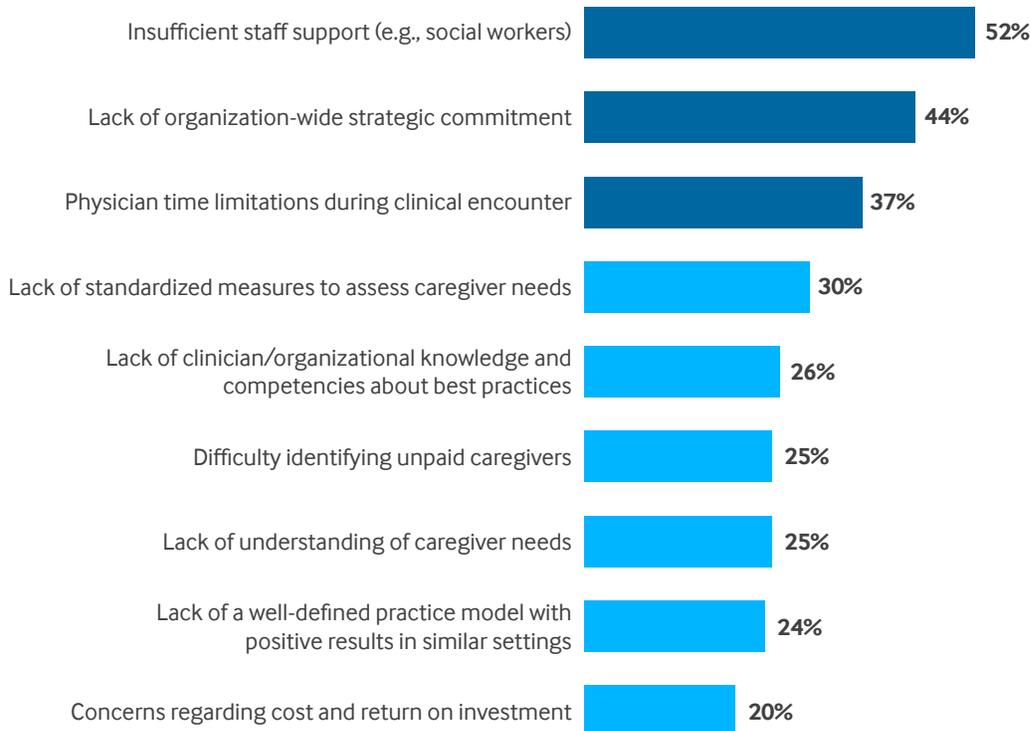
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“ Respondents say that care coordination and navigation assistance initiatives are their top and most useful resources — but they also understand that care navigation is overly complex and recognize there is limited coordination with social services and community-based organizations. ”

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## Staffing Is the Top Barrier to Addressing Caregiver Needs

What are the top three barriers at health care organizations to addressing unpaid caregiver needs and providing support?



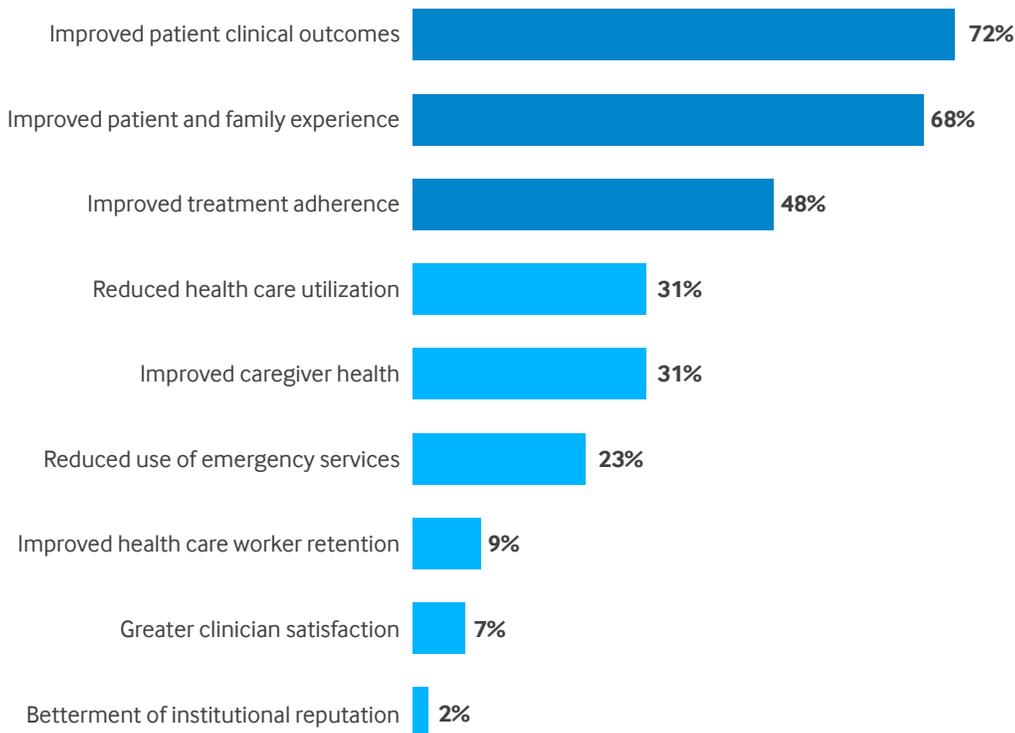
Base: 386 (multiple responses)

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The top barrier to addressing unpaid caregiver needs and providing support for U.S.-based respondents is insufficient staff support (e.g., social workers), chosen by 52%. For survey respondents outside the United States, the top barrier is lack of organization-wide strategic commitment (46%). One clinician suggests giving “more concentrated time with attentive listening to the caregiver upfront in order to gather the entire picture of the caregiver and environmental situation.”

## Multiple Benefits to Health Care Organizations in Meeting Unpaid Caregiver Needs

What are the top three benefits to health care organizations of meeting unpaid caregiver needs?



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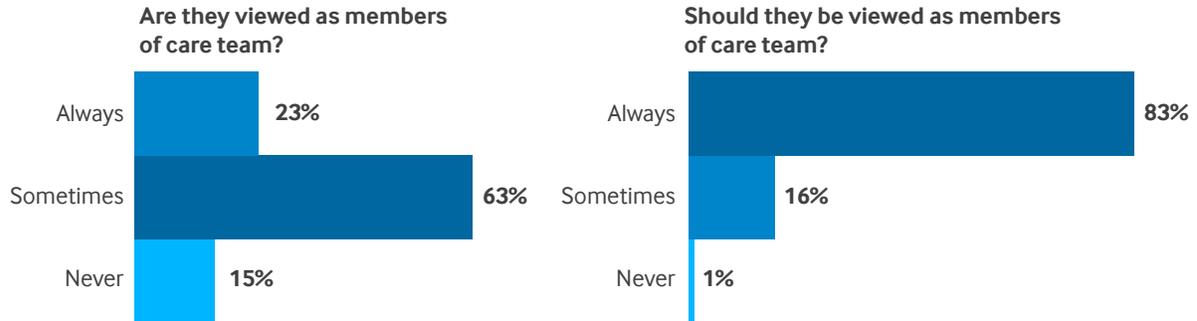
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Insights Council members say there are substantial clinical outcomes in meeting unpaid caregiver needs, as well as improved patient and family experience. An executive writes that organizations should acknowledge “the caregiver’s contributions to the patient’s overall standard of care and improved outcome.”

## Caregivers Should Be Part of the Care Team – but Often Are Not

Are unpaid caregivers viewed as members of the care team at your organization?

Should they be viewed as members of the care team ?



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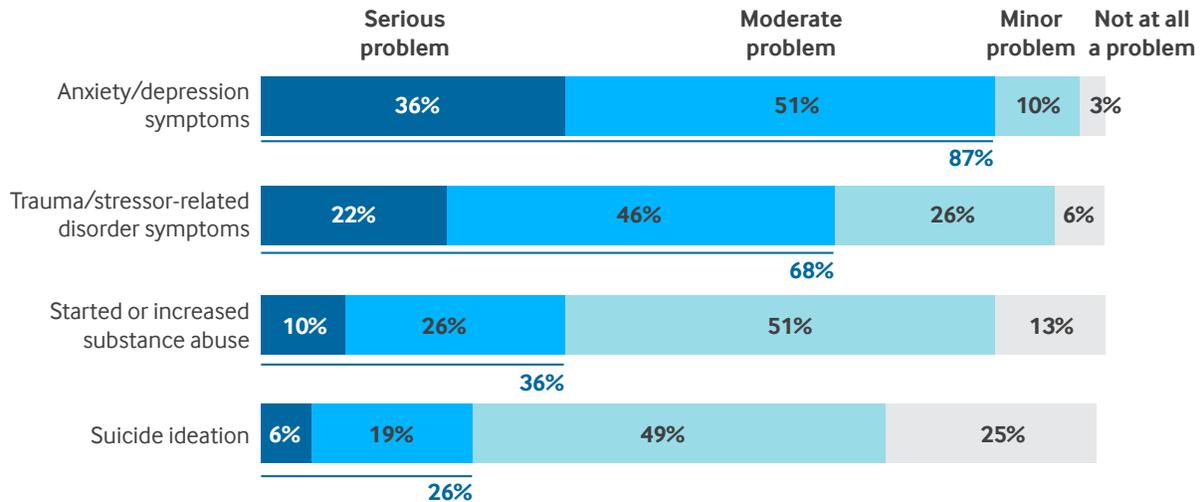
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While just under a quarter of respondents say that unpaid caregivers are always viewed as members of the care team, a strong majority (83%) say they should be. “We need to treat the unpaid caregiver, who is usually family of the patient, as our own family, as a vital part of the care team. They do more, they get no support, and they are emotionally, and usually financially drained. I see it daily,” one clinician writes.

“ Everything is great for the first 24 hours — it’s after that when the patient and caregiver need help.

## Unpaid Caregivers Experience Significant Mental and Behavioral Issues

To what extent are the following behavioral and mental health issues a problem for unpaid caregivers served by your organization?



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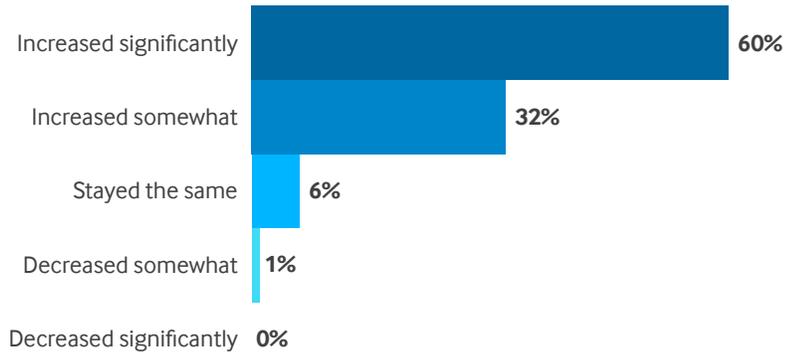
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Survey respondents observe that unpaid caregivers experience considerable behavioral and mental health issues. A clinical leader comments that providers should give unpaid caregivers “the education and resources they need to give the best care while maintaining good physical and mental health.” A clinician recommends practicing “empathy to caregiver problems in addition to patients.”

“Caregivers who know respite services exist for them, even if they don’t use them, experience 70% less stress.”

## The Covid-19 Pandemic Has Worsened Mental and Behavioral Health Issues

What impact has the Covid-19 pandemic had on behavioral and mental health issues for unpaid caregivers served by your organization?



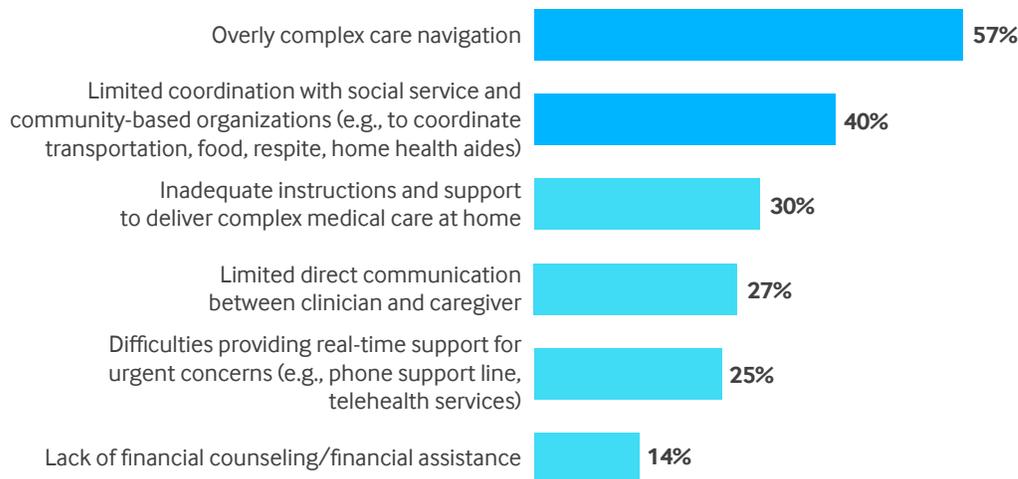
Base: 386

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The Covid-19 pandemic has worsened behavioral and mental health issues for unpaid caregivers, according to respondents. “Take the time to recognize [caregivers] are people trying to do the best they can while supporting their family/friend and dealing with the complexities of the world,” a clinician writes.

## Health Care Complexity Contributes to Unpaid Caregiver Stress

What are the top two ways the health care industry contributes to unpaid caregiver stress?



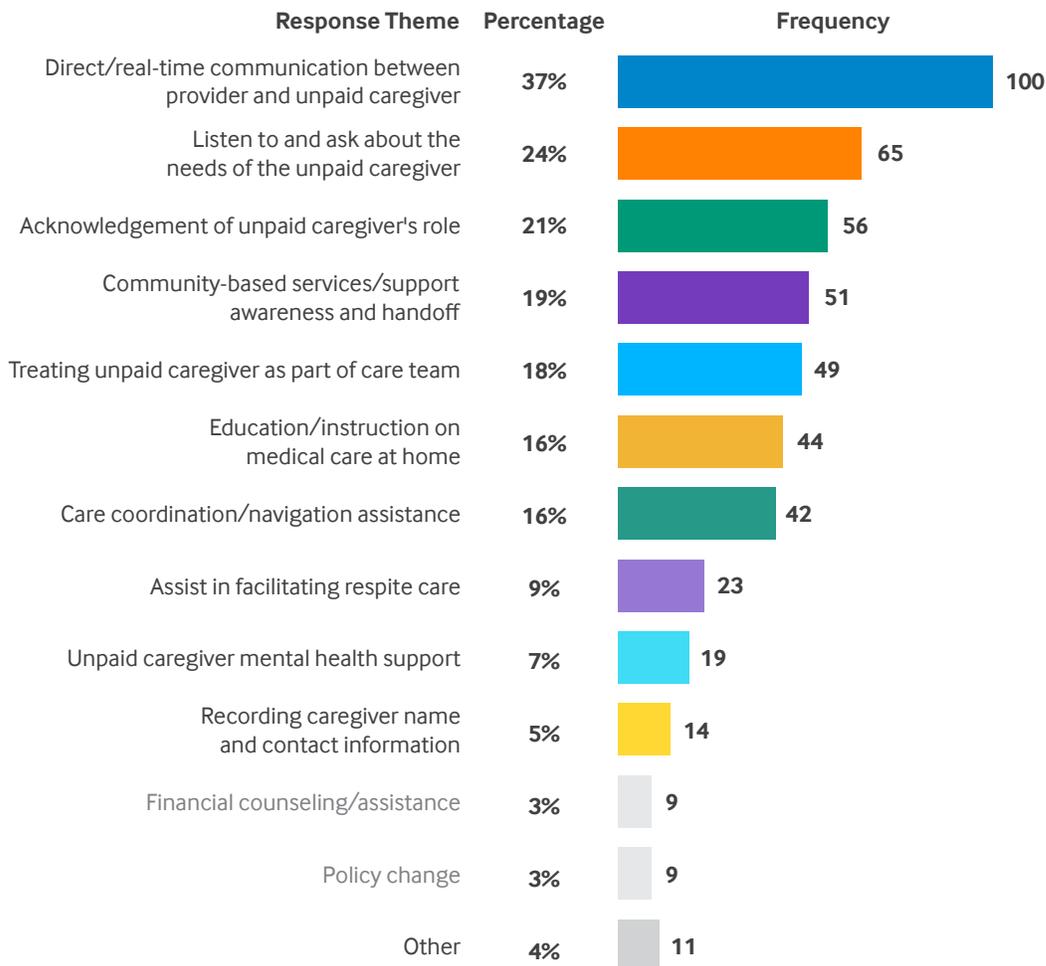
Base: 386 (multiple responses)

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Insights Council members say that the health care industry contributes to unpaid caregiver stress. But overly complex care navigation is far greater a problem in the United States — selected by 57% of U.S.-based respondent versus 24% of non-U.S. respondents. An executive recommends institutionalizing caregiver navigation programs that “establish goals of care for the caregiver [and] help the caregiver define what is a good day and how to work towards achieving that.”

## Verbatim Comments from Survey Respondents

What is the single most important way in which health care providers should support unpaid caregivers?



Base: 386 (percentages do not add to 100 as some answers fall in multiple categories)

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## Direct/real-time communication between provider and unpaid caregiver

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| *Increased availability — by phone, in person, telehealth, emails.*

— Vice President from a nonprofit in the West

| *Provide 24/7 contact information and support to solve immediate problems and to arrange contact after crises.*

— Clinician at a nonprofit community hospital in the Midwest

| *Communicate consistently and frequently on how to care for the patient and provide community and social service resource connections for the caregiver.*

— Clinician at a for-profit clinic in the South

## Listen to and ask about the needs of the unpaid caregiver

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| *Take the time to recognize they are people trying to do the best they can while supporting their family/friend and dealing with the complexities of the world. Often people do not think about others or really what they are going through unless they are in the situation themselves. Empathy, compassion, and true caring is essential. Often there is a check-box mentality to case management services. Assessed and done. No outside of the box thinking.*

— Nurse practitioner at a nonprofit health system in the South

| *Give more concentrated time with attentive listening to the caregiver upfront in order to gather the entire picture of the caregiver and environmental situation, i.e. a helicopter view of the caregiver's situation.*

— Clinician at a for-profit provider in the Northeast

## Acknowledgement of unpaid caregiver's role

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| *Acknowledge that they provide most of the care, and treat them with respect beginning with accessible communication.*

— Chief Medical Officer at a for-profit physician organization in the West

| *Validate their caring and diligence.*

— Clinician at a nonprofit medical school in the West

## Community-based services/support awareness and handoff

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*Give them the education and resources they need to give the best care while maintaining good physical and mental health.*

— Chief Medical Officer at a nonprofit medical school in the South

*Provide guidance and support in arranging additional caregiving resources in home and community.*

— Physician at a nonprofit teaching hospital in the Northeast

## Treating unpaid caregiver as part of care team

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*The single most important way to support unpaid caregivers is to treat them as respected members of the care team. This means delivering education and guidance that is understandable and expands past the immediate condition to create a conversation that recognizes the value of the unpaid provider. The goal of such an approach includes activating and engaging them with resources that allow them to monitor with confidence, to deliver care that meets the needs of the patient. Unpaid caregivers are among the most important members of the team with exceptionally deep knowledge of the patient, far more depth than can ever be achieved with an EMR.*

— Senior executive at a nonprofit provider in the Northeast

*We need to treat the unpaid caregiver, who is usually family of the patient, as our own family, as a vital part of the care team. They do more, they get no support, and they are emotionally, and usually financially drained. I see it daily. Then, as a society, we shame them for putting their loved on in a group care situation. Often those situations are unhealthy for the patient, poorly run, full of resistant micro-organisms, and neglectful. So, why do other countries get it right, while we treat our ill and infirm like throw aways? I do not know.*

— Clinician at a for-profit clinic in the South

## Education/instruction on medical care at home

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*Clear, written instructions about exactly what needs to be done when the patient gets home. These must be SPECIFIC to each patient, not some tear sheet about all abdominal wounds or whatever.*

— CEO at a nonprofit health system in the South

*The caregiver role is akin to having a chronic condition which may worsen over time. Institutionalized caregiver navigation programs that establish goals of care for the caregiver. Help the caregiver to define what is a good day and how to work towards achieving that.*

— Vice President at a nonprofit teaching hospital in the West

### Care coordination/navigation assistance

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*Improve referral patterns and understand the community resources for caregivers in our community.*

— Clinician at a nonprofit clinic in the Midwest

*Provide a warm handoff to a care navigator who can connect the unpaid caregiver with community resources and even access to payment or support for days off.*

— Clinician at a nonprofit teaching hospital in the West

### Assist in facilitating respite care

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*Respite — everyone needs a break and to know that their loved one is safe.*

— Chief Medical Officer at a for-profit health plan in the South

*Making resources available for mental and physical health in the form of respite programs and financial counseling, including guidance on how to financially afford or access health aides and at home care for patients who are family members.*

— Clinician at a nonprofit health system in the Northeast

### Unpaid caregiver mental health support

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*Ask caregiver about stressors and issues and connect to community based services/supports.*

— Vice President at a nonprofit health plan in the Midwest

### Recording caregiver name and contact information

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*Recognize their position in the health team and create a distinct communication pathway for them. Without recognition, no other support is possible.*

— Clinician at a nonprofit clinic in the Northeast

## Methodology

- The *Caring for Caregivers* survey was conducted by NEJM Catalyst, powered by the NEJM Catalyst Insights Council.
- The NEJM Catalyst Insights Council is a qualified group of executives, clinical leaders, and clinicians at organizations worldwide who are directly involved in health care delivery.
- In March 2021, an online survey was sent to the NEJM Catalyst Insights Council.
- A total of 386 completed surveys are included in the analysis. The margin of error for a base of 386 is +/- 5.0% at the 95% confidence interval.

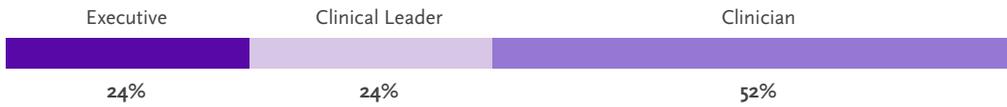
## NEJM Catalyst Insights Council

We'd like to acknowledge the NEJM Catalyst Insights Council. Insights Council members participate in monthly surveys with specific topics on health care delivery. These results are published as NEJM Catalyst Insights Reports, such as this one, including summary findings, key takeaways from NEJM Catalyst leaders, expert analysis, and commentary.

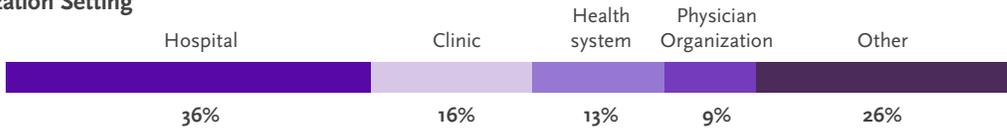
It is through the Insights Council's participation and commitment to the transformation of health care delivery that we are able to provide actionable data that can help move the industry forward. To join your peers in the conversation, visit <https://catalyst.nejm.org/insights-council>.

## Respondent Profile

### Audience Segment



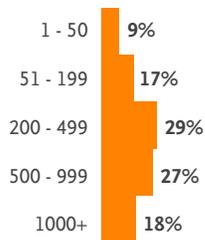
### Organization Setting



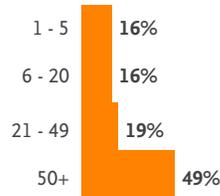
### Type of Organization



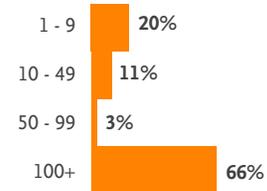
### Number of Beds (Among hospitals)



### Number of Sites (Among health systems)



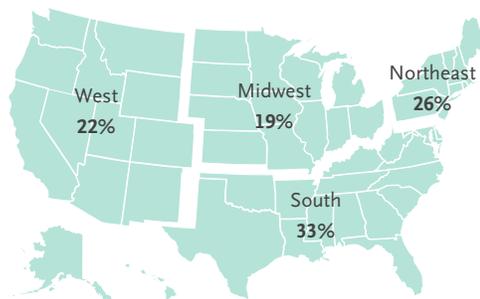
### Number of Physicians (Among physician organizations)



### Net Patient Revenue



### Region



Base = 386

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## About Us

NEJM Catalyst brings health care executives, clinical leaders, and clinicians together to share innovative ideas and practical applications for enhancing the value of health care delivery. From a network of experts and advisors, our digital peer-reviewed journal, live-streamed events, and qualified Insights Council provide real-life examples and actionable solutions to help organizations address urgent challenges affecting health care.



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NEJM CATALYST INNOVATIONS IN CARE DELIVERY

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