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carers

The Global Carer Well-Being Index

Who Cares for Carers? Perspectives on COVID-19
Pressures and Lack of Support



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“Due to the pandemic, you are forced to wear a mask and a person with dementia **forgets this, so every day is like the pandemic started today.**”

– 55-year-old Male from Germany taking care of someone with Dementia

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Setting the Stage



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According to the International Alliance of Carer Organizations (IACO), there are more than 63 million carers internationally*. In order to illuminate the challenges carers face, [Embracing Carers™](#), a collaboration with leading carer organizations around the world, conducted a Global State of Care survey in 2018 to determine the unmet needs of carers and the impact that caring for others has on their own health and well-being. The collaboration and key findings from the research sought to increase awareness, discussion and action about the often-overlooked needs of people who provide unpaid care for others.

Around the globe, many of the stresses on carers have long existed, but in 2020, the uncertainty of the pandemic has made them even greater for carers across countries. It has significantly affected global healthcare systems and has caused substantial disruption for unpaid carers around the world, in ways that put their economic, physical and psychological well-being at risk.

In producing the 2020 Carer Well-Being Index, Embracing Carers aims to detail the ways in which the pandemic disproportionately harms carers around the globe—and to identify key societal solutions and specific actions that can address their needs during the pandemic and beyond.

*The Carer Well-Being Index serves as a resource with insights and solutions to help the public and private sector better support unpaid carers around the world.

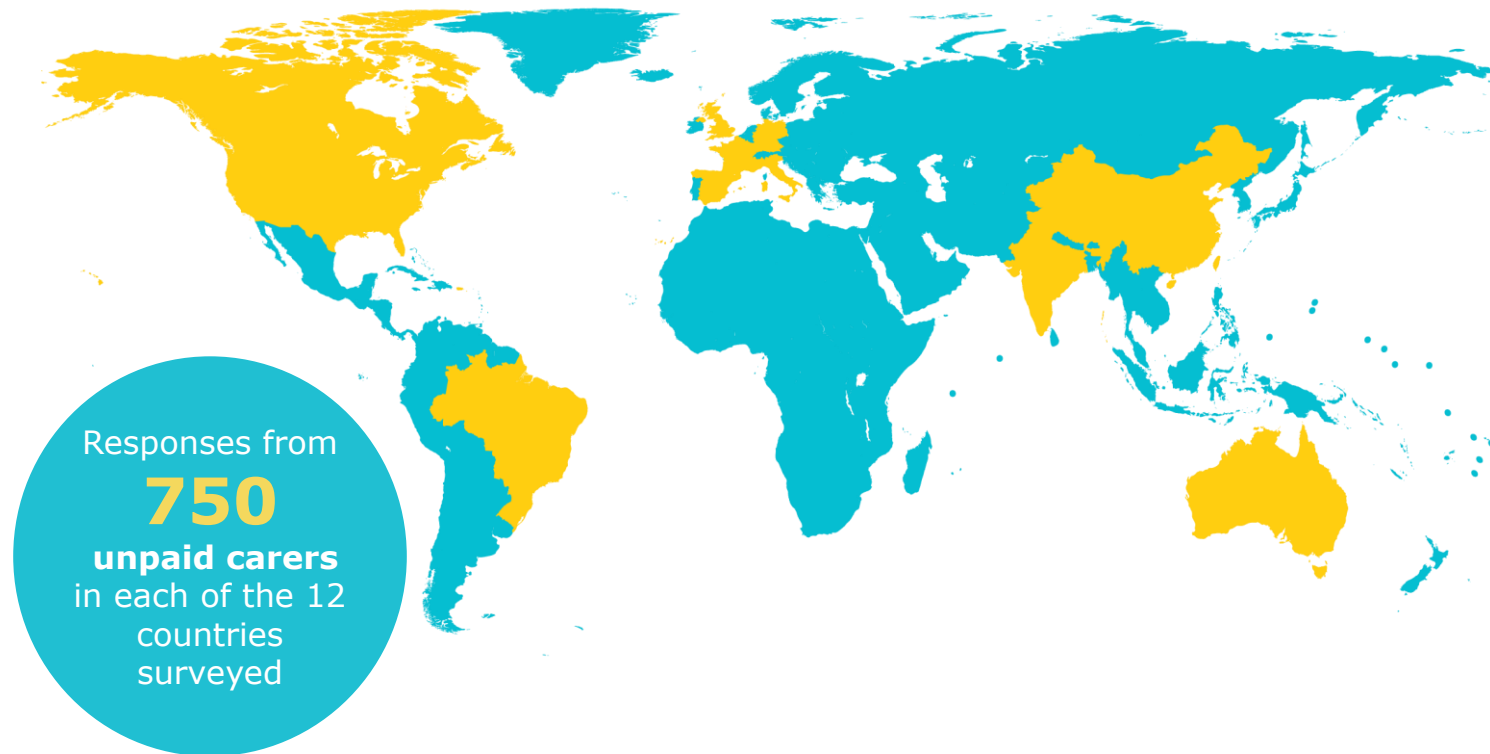
*Merck KGaA, Darmstadt, Germany operates its biopharmaceutical business in the U.S. and Canada as EMD Serono.

Research approach and methodology*

The Carer Well-Being Index is a **global** research study commissioned by Embracing Carers and fielded in partnership with an independent, third-party market research provider and non-governmental organizations across **12 countries**: United States, Canada, United Kingdom, France, Germany, Italy, Spain, Australia, Brazil, Taiwan, India and China.

Respondents included more than **9,000 unpaid carers (or “caregivers”)** across the countries surveyed **who care for someone with a long-term illness, physical disability, or cognitive/mental condition**. The conditions they care for included cancer, Multiple Sclerosis, Parkinson’s Disease, Dementia, Alzheimer’s, Spinal cord injury, Muscular Dystrophy, other cognitive/mental condition or Congestive Heart Failure.

Unless otherwise noted, **the content in this report showcases global learnings**, referred to as the 12-country average[^], of the carers surveyed internationally.



The study was fielded September 3 – October 27, 2020 via online and phone methodologies. Outgoing sample collected was balanced to each country’s Census to allow qualifying respondents to fall out naturally. Light weighting was applied in select countries to achieve better national representation. At the 95% confidence level, the full global unpaid carer sample has an estimated margin of error of +/- 1.03 percentage points.

*For further details on the methodology and demographic profile of the global carer respondents surveyed, please visit the Appendix.

[^]The 12-country average represents the mean quotient, obtained by summing the total set of responses and then dividing by 12 (which is the total set of countries surveyed) to obtain an average score.

Five key themes emerged from the 2020 Carer Well-Being Index



Rising Demands

The pandemic sent shockwaves across the globe and placed added pressure on carers. More than ever before, they are shouldering heavy burdens.



Changed Responsibilities

Carers around the world have long faced hurdles, but the pandemic has elevated specific tasks, amplifying their responsibilities.



The Toll on Carers

Though being a carer can be rewarding, it comes at a cost. The physical, mental, financial, social and career implications can combine to erode carers' well-being.



Inequities Impacting Carers around the World

All carers are facing difficult times, but they vary by generation, and women face their own unique struggles.



Path to Solutions

Supporting carers is a global issue and a societal responsibility. Across public and private sectors, everyone has a role to play.



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“Overall, my tasks increased, I had to distract them from what was going on as well as **create more comfortable situations that didn't require leaving the house.**”

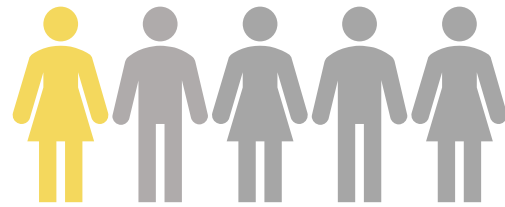
-40-year-old Female from Brazil taking care of someone with an ongoing long-term cognitive/mental condition

I: Rising Demands

The coronavirus pandemic has dramatically heightened the demand for carers and increased their responsibilities. What does that look like through their eyes?

- Many are young adults and parents who have become carers for the **first time** in their lives during the pandemic.
- Most of the need is in their own homes—often to care for their own **parents**.
- The demand for carers shot up dramatically when COVID-19 hit and will continue to **grow** in the years ahead.
- There are many physical dimensions to caregiving, but the greatest responsibility they face is **emotional** support.
- Carers know they face a hard job. Most find it rewarding. But they don't all feel **valued**.

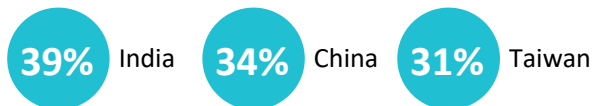
As the pandemic spread across the globe, many younger adults became carers for the first time



20%

became a carer for the **first time** as a result of the pandemic

Carers in the countries below were more likely than the 12-country average (20%) to become first time carers as a result of the pandemic:



Younger generations and parents are more likely to be first time carers as a result of the pandemic

25%



of Gen Z/ Millennial

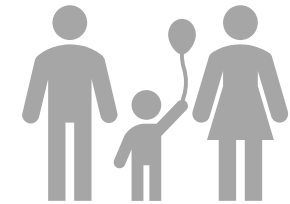
vs.

15%



Of Gen X/ Boomers

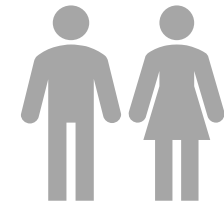
25%



Of Parents

vs.

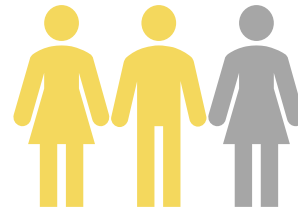
15%



Of Non-parents

Many of these carers fall into the **sandwich generation***, which is a generation typically in their thirties or forties, responsible for **bringing up their own children and for the care of their aging parents.**

Carers are often taking care of people within their own homes—predominately their parents



Caring for a household member

67% of carers are the primary unpaid carer for a household member.



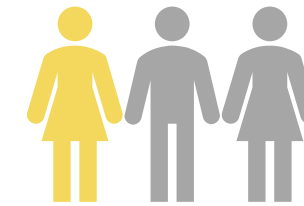
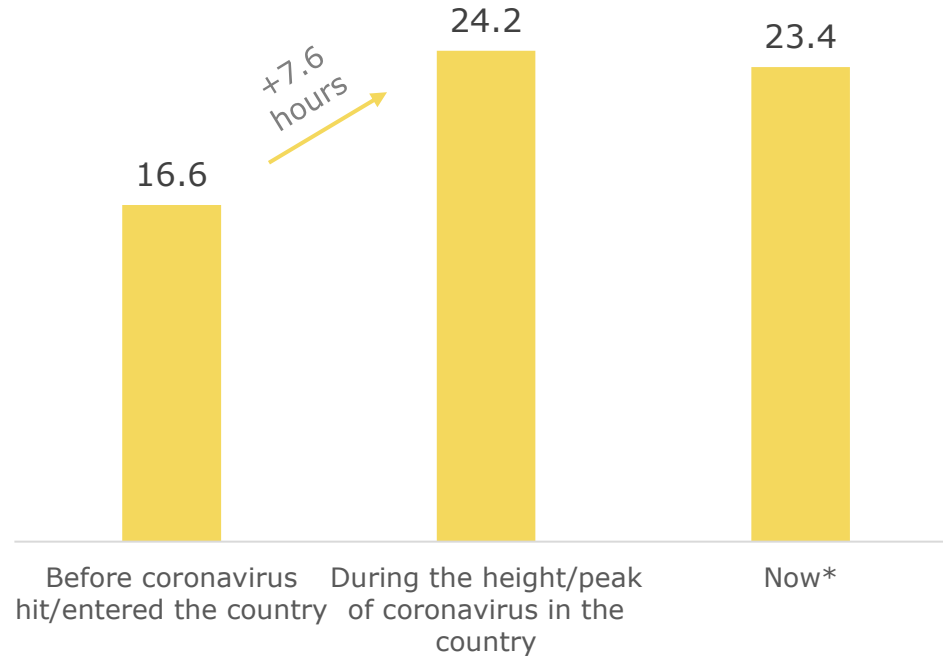
Caring for their parents

48% of carers are caring for their parents.

In **Taiwan**, those caring for parents (**69%**) is significantly higher than the 12-country average (48%). This may be attributed to its super-aged society where at least 20% of its population are age 65 or older*.

Around the world, the demand on carers' time has grown exponentially and is expected to continue growing for the foreseeable future

Average Hours Carers Spend on Caregiving (per week)



31+ Hours

33% of carers believe they will be spending, on average, **31+ hours** a week on caregiving in the future due to the impact of the coronavirus.

*Now refers to Fall 2020 when the survey was fielded

Q8. On average, how many hours did/do you spend per week on caregiving during each of the following timeframes? Please provide your best estimates. Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n=755; Taiwan n=753; India n=750; China n=754

Q25. On average, how many hours do you think you'll be spending per week on caregiving in the future due to the impact of the Coronavirus/COVID-19 pandemic? Base: 12-Country Total n=9044

While demand on time has increased globally due to the pandemic, Asian carers are experiencing the greatest caregiving time increase

Average Hours Carers Spend on Caregiving by Country (per week)

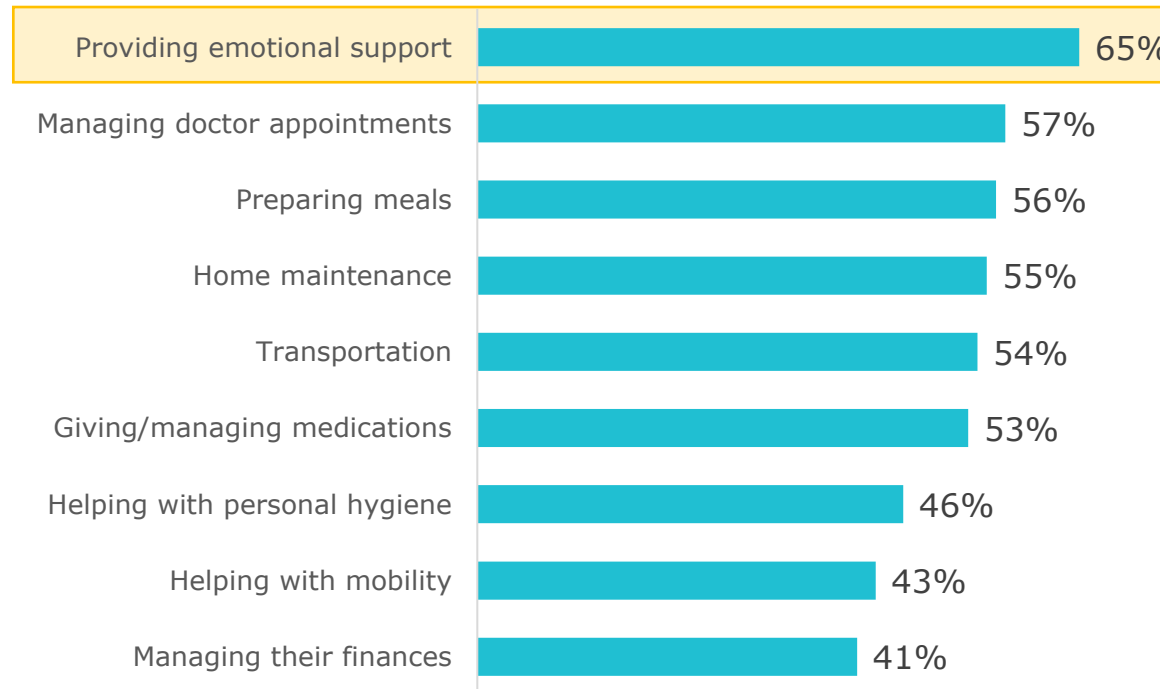
| | Before the pandemic | Now* | Change in hours |
|------------------|---------------------|------|-----------------|
| Taiwan | 14.9 | 29.7 | +14.8 |
| China | 12.9 | 25.3 | +12.4 |
| India | 12.6 | 21.8 | +9.2 |
| Brazil | 17.7 | 25.1 | +7.4 |
| USA | 20.6 | 28 | +7.4 |
| Spain | 17.2 | 23 | +5.8 |
| Canada | 16.8 | 21.6 | +4.8 |
| Italy | 18.5 | 23.1 | +4.6 |
| UK | 21.3 | 25.9 | +4.6 |
| Germany | 14 | 17.8 | +3.8 |
| Australia | 17.6 | 21.3 | +3.7 |
| France | 14.6 | 18.1 | +3.5 |

Those who are carers in Taiwan, China and India are experiencing the greatest increases in time demands across the 12 countries surveyed.

*Now refers to Fall 2020 when the survey was fielded

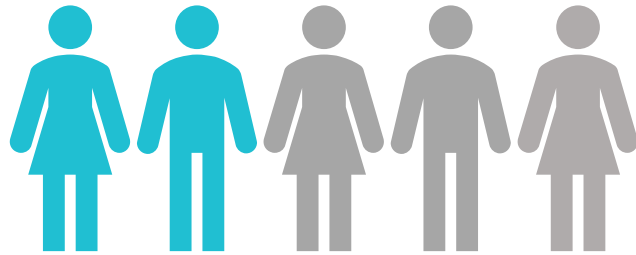
Amid trying and uncertain times, carers' biggest responsibility is in providing emotional support

Top Responsibilities as a Carer:



Carers who say that providing emotional support is a top responsibility as a carer is higher in the United States (77%) and the United Kingdom (73%).

Carers are being relied on more than ever before

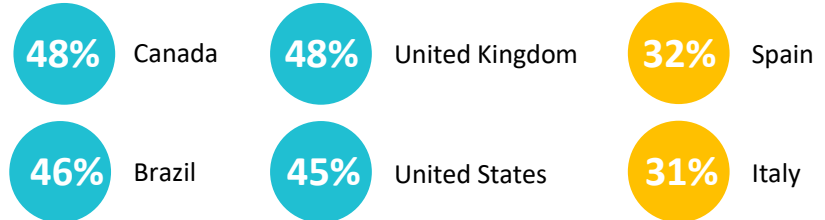


39%

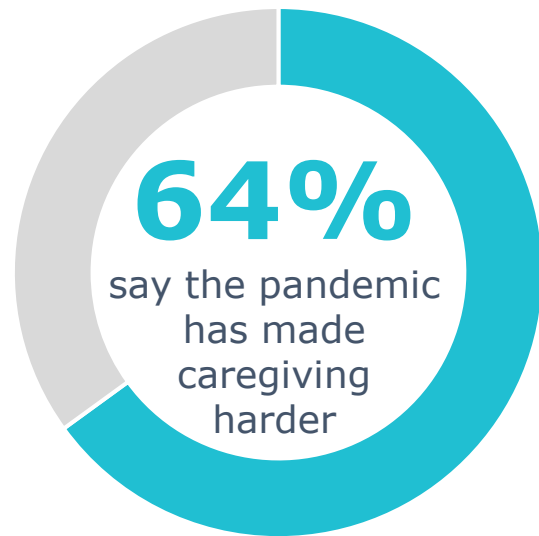
say the person(s) they care for is/are **relying on them more than ever before**

Compared to the 12-country average (39%), carers in **Canada, United Kingdom, Brazil** and **the United States** are more likely to say the person they care for is relying on them more than ever before during the pandemic.

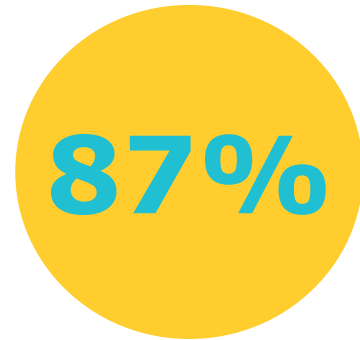
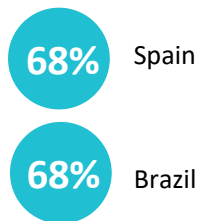
Carers in **Spain** and **Italy** are least likely to say this.



Many carers say the pandemic has made their caregiving role harder and appreciation is lacking, however they still find it rewarding

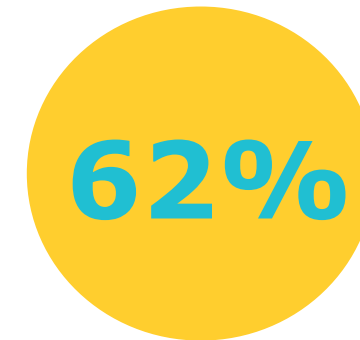
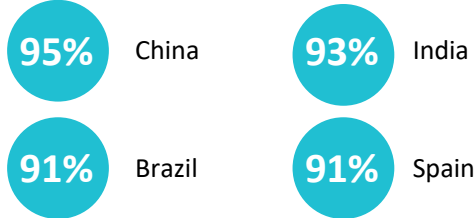


Carers in the countries below are more likely to say the pandemic has made caregiving harder:



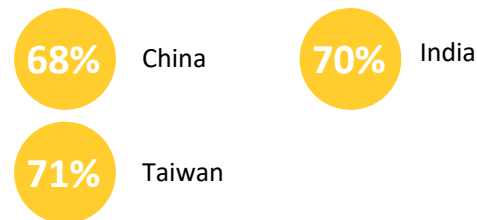
agree that caring for someone during the Coronavirus is hard but it is also very rewarding

Carers in the countries below are more likely to agree:



say that the person(s) they care for is/are NOT appreciative of their efforts

Carers in the Asian countries below are even more likely to say this:



“You will get through it as difficult as it is. It is rewarding knowing you are helping and protecting the one you love.”

- 57-year-old female from Canada taking care of someone with severe arthritis

Q9. In general, would you say the Coronavirus/COVID-19 pandemic has made caregiving harder or easier? Base: 12-Country Total n=9044; Spain n=751; Brazil n=755

Q14. Which, if any, of the following statements is true for you as it relates to how the Coronavirus/COVID-19 pandemic has impacted your ability to provide care? Select all that apply. Base: 12-Country Total n=9044; China n=754; India n=750; Taiwan n=753

Q24. To what extent, if at all, do you agree with each of the following statements: - Agree Summary Base: 12-Country Total n=9044; China n=754; India n=750; Brazil n=755; Spain n=751

Q30. What message(s), if any, would you want to give other carers/carers as they are managing caregiving responsibilities during the Coronavirus/COVID-19 pandemic? Base: 12-Country Total n=9044



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*I have to make sure that she is **emotionally healthy and feels supported, be encouraging** and deal with her fears of the Coronavirus.”*

– 53-year-old Female from India taking care of someone with paralysis



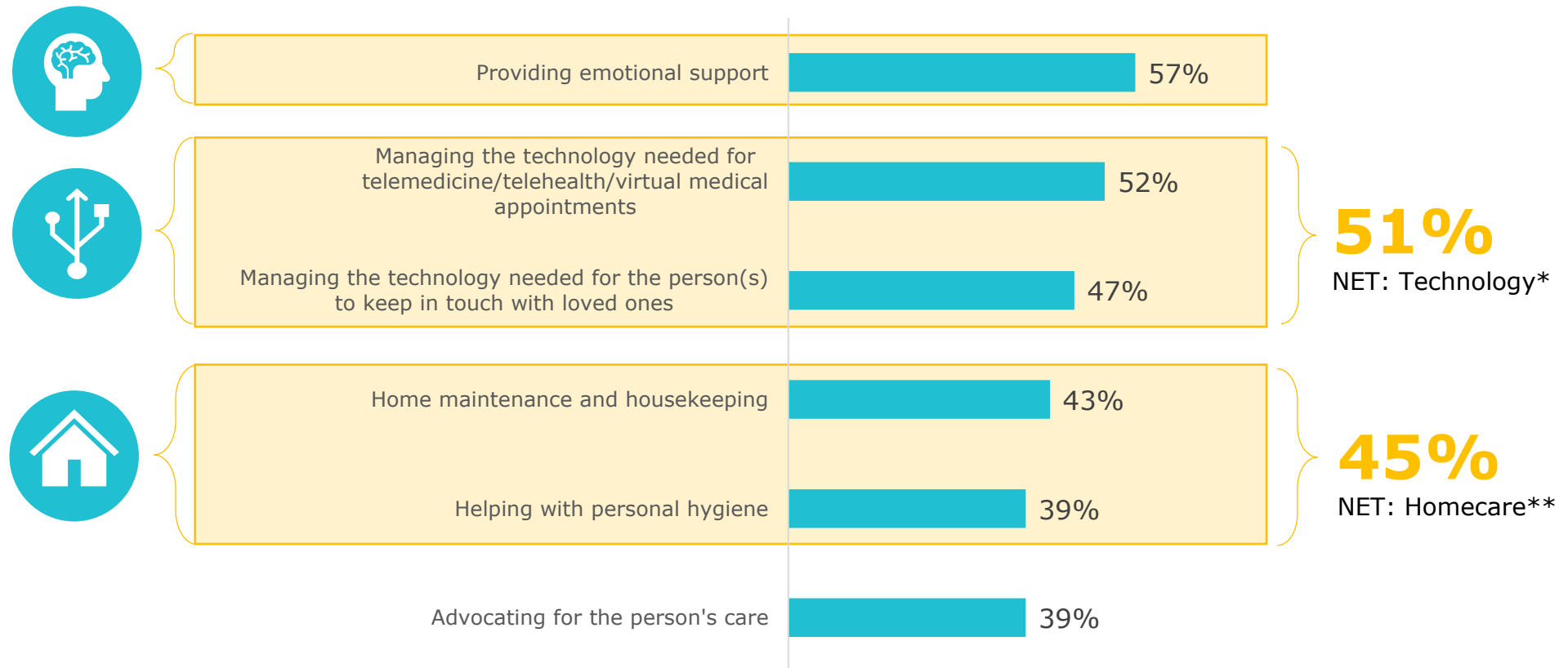
II: Changed Responsibilities

The need for care isn't the only thing that's changing. The pandemic is accelerating the evolving nature of caregiving— with more challenges adding more pressure.

- The demand for carers to provide emotional support is **greater than** it was in most countries before COVID-19.
- With more care happening in the home, **housework and home maintenance** are a growing part of the job.
- As the needs of those they care for grow deeper, almost nine out of ten carers are **putting their own needs second**.
- Some need help mastering the **technology** that goes into caring.
- Carers always need respite, but with pandemic quarantines in place, they're finding fewer opportunities to **take breaks**.

Carers around the world are facing three key pressure points: emotional support, technology, and homecare

Top Responsibilities That Have Increased Due to the Pandemic:



*Managing technology NET consists of the total respondents who chose 'managing the technology needed for telemedicine/telehealth/virtual medical appointments' and/or 'managing the technology needed for the person(s) to keep in touch with loved ones' as top responsibilities that have increased due to the pandemic.

**Homecare NET consists of total respondents who chose either 'home maintenance and/or housekeeping' and/or 'personal hygiene' as top responsibilities that have increased due to the pandemic.

Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: 12-Country Total n=9044



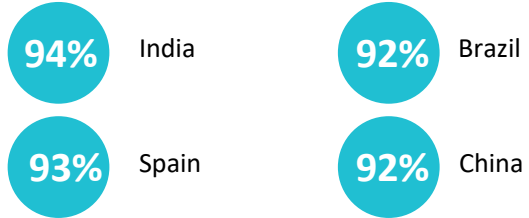
As the pandemic spreads, emotional support needs surge, and self-care takes a backseat



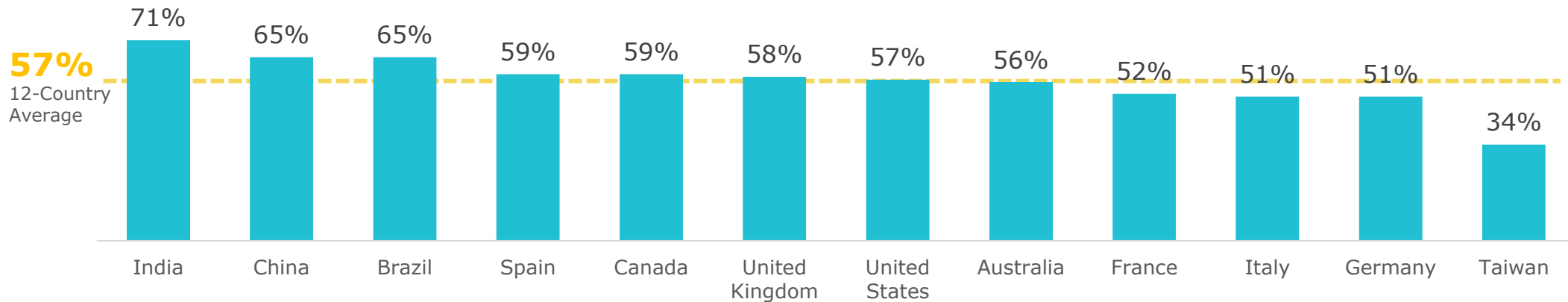
89%

say they've put the **needs of the person(s)** they are caring for above their own **during the pandemic**

Carers in the countries below are more likely to say this:



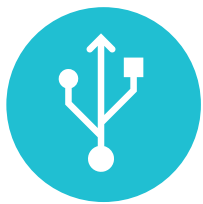
Increased Due to the Pandemic Summary: Providing Emotional Support



Carers in **India**, **China** and **Brazil** are more likely than other countries to experienced a surge in providing emotional support during the pandemic.

Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: Those who responded that they 'provide emotional support' 12-Country Total n=5874; United States n=576; Canada n=547; United Kingdom n=551; France n=527; Germany n=474; Italy n=464; Spain n=541; Australia n=474; Brazil n= 537; Taiwan n=414; India n=384; China n=385
Q24. To what extent, if at all, do you agree with each of the following statements: - Agree Summary Base: 12-Country Total n=9044; India n=750; Brazil n=755; Spain n=751; China n=754



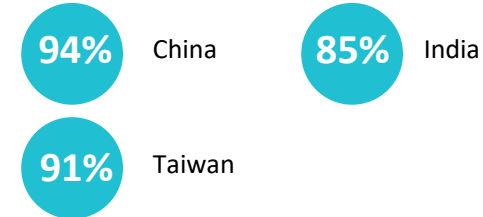


Telehealth and technology usage is increasing for carers around the globe – but many need further guidance

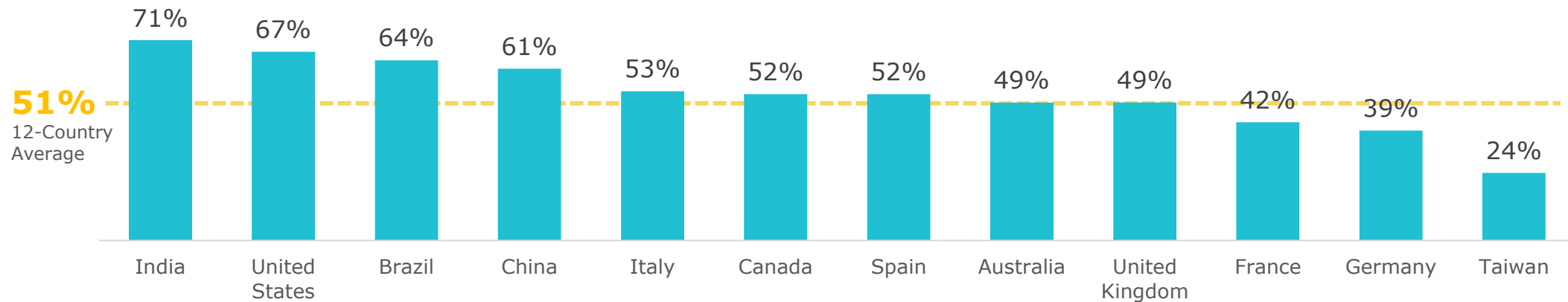


68% of carers need **additional guidance/training on how to use telehealth/online tools/mobile apps** for caregiving

Carers of the Asian region are more likely than the 12-country average to desire greater guidance and training on telehealth resources for caregiving.



Increased Due to the Pandemic Summary: Managing Technology*



More than the 12-country average, carers in **India, the United States and Brazil** have experienced a greater demand to manage technology for telehealth. Also above the average, **China, Taiwan and India** are most inclined to crave additional guidance and trainings on these technologies.

*Managing technology NET consists of the total respondents who chose 'managing the technology needed for telemedicine/telehealth/virtual medical appointments' and/or 'managing the technology needed for the person(s) to keep in touch with loved ones' as top responsibilities that have increased due to the pandemic.
Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: Those who responded that they 'manage the technology needed for telemedicine/telehealth/virtual medical appointments' (12-Country Total n=2156; United States n=243; Canada n=183; United Kingdom n=178; France n=174; Germany n=121; Italy n=136; Spain n=213; Australia n=213; Brazil n= 196; Taiwan n=196; India n=174; China n=129) Those who responded that they 'manage the technology needed for the person(s) to keep in touch with loved ones' (12-Country Total n=2694; United States n=289; Canada n=247; United Kingdom n=236; France n=239; Germany n=196; Italy n=192; Spain n=218; Australia n=249; Brazil n= 261; Taiwan n=217; India n=192; China n=157)
Q16. To what extent, if at all, do you agree with each of the following statements: - Agree Summary Base: 12-Country Total n=9044; China n=754; India n=750; Taiwan n=753

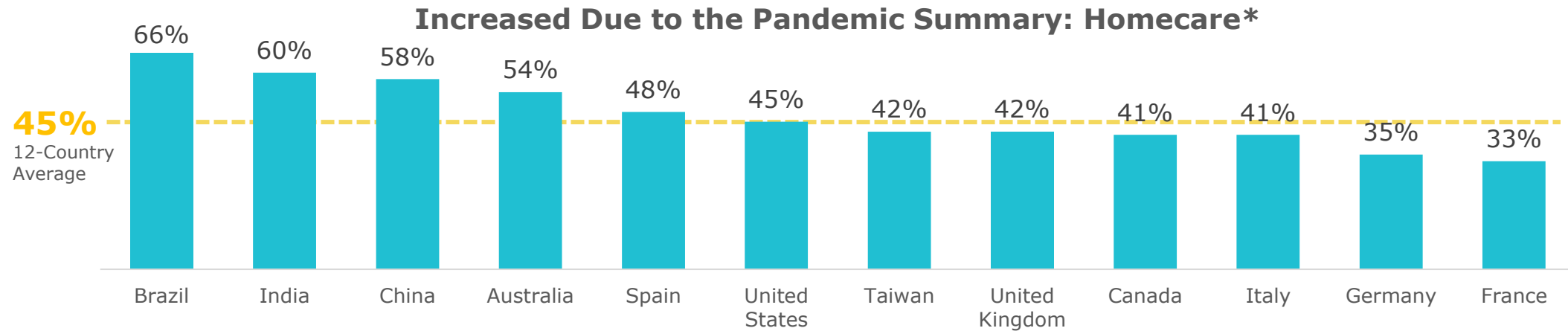




While the world quarantines, carers' responsibilities at home grow—leaving little time for respite

23% say the **biggest challenge** they've faced as a carer during the pandemic is the **inability to take a break**

Carers in the countries below are more likely to say this:



Homecare has become a greater demand for carers particularly in **Brazil, India and China.**

*Homecare NET consists of total respondents who chose either 'home maintenance and/or housekeeping' and/or 'personal hygiene' as top responsibilities that have increased due to the pandemic.
 Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: Those who responded that their responsibilities are 'home maintenance and/or housekeeping' (12-Country Total n=5000; United States n=502; Canada n=484; United Kingdom n=489; France n=442; Germany n=398; Italy n=398; Spain n=467; Australia n=434; Brazil n= 435; Taiwan n=381; India n=347; China n=223) Those who responded that their responsibilities are 'helping with personal hygiene' (12-Country Total n=4134; United States n=381; Canada n=264; United Kingdom n=357; France n=293; Germany n=296; Italy n=344; Spain n=409; Australia n=258; Brazil n= 385; Taiwan n=361; India n=367; China n=418)
 Q13. Which, if any, of the following are the biggest challenges you've faced as a carer/carer during the Coronavirus/COVID-19 pandemic? Please select top three. Base: 12-Country Total n=9044; United Kingdom n=755; United States n=750



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III: The Toll on Carers

For the people who need them, carers offer indispensable services that are hard to quantify. But the carers themselves can suffer a number of harms—emotional, financial, professional, physical and social—in the process.

- **Sacrifice and burnout** are common among carers, especially at the beginning.
- Caring puts people in a **financial squeeze** between higher expenses and reduced income from damaged careers, often with inadequate public support.
- Carers' **physical health** suffers from lack of sleep and exercise.
- Caring means a closer relationship with one person or persons—and diminished relationships with other friends and loved ones. Feelings of **social isolation** are common.

“There are certain situations when I have had to **postpone my own care or personal needs in order to accommodate my father.**”

– 51-year-old Female from the United States taking care of someone with Cancer

Most carers are experiencing unprecedented levels of burnout, particularly first-time carers



81%

of carers have had to **sacrifice more of their personal life** for the individual(s) they care for

This is even **higher among first time carers as a result of the pandemic** (91%), as well as those in **China** (91%) and **Spain** (84%).



76%

of carers say caring for someone during the pandemic has caused them to **feel more burnt out than ever before**

This is even **higher among first time carers as a result of the pandemic** (86%), as well as those in **China** (85%), **Brazil** (83%) and **Spain** (82%).

The pandemic is deeply affecting multiple aspects of carers' well-being

1

Emotional/Mental
Well-Being



2

Financial
Well-Being



3

Professional
Well-Being (Career)



4

Physical
Well-Being



5

Social
Well-Being





Isolation, limited time with loved ones and fear of death overwhelm carers amid the pandemic

61%

of carers say the pandemic has worsened their emotional/mental health

Even higher for carers in **Spain** (74%), as well as **Canada**, **Brazil** and the **United Kingdom** (70% each).

Top Reasons for worsening emotional/mental health during the pandemic (among carers whose emotional/mental health worsened)

| | Physical distancing/ sequestering orders have made me feel isolated and alone | I have even less time to spend with my family and friends | I am more afraid than ever before that the person/ people I care for is/are going to die |
|---|---|---|--|
| Lowest to Highest relative to Global Average^ | 44% Canada | 39% Canada | 40% Italy |
| | 39% United States | 38% United Kingdom, Spain, Australia each | 38% Brazil |
| | 34% 12-country average | 31% 12-country average | 31% 12-country average |
| | 27% India | 23% India | 21% India |
| | 27% Taiwan | 16% China | 20% Taiwan |

Asian countries are least likely to follow the global trends around why their emotional health has worsened. Instead, carers from **Taiwan** point to being anxious about balancing their paid job/work and caregiving responsibilities (39%), compared to 29% globally, and **Indian** carers are worried about having enough money to pay for everything they need for the individual(s) they care for (38%), compared to 28% globally.

[^]Data demonstrates the countries that were highest and lowest in relation to the 12-country global average.
 Q12. In general, do you feel Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: 12-Country Total n=9044; Spain n=751; Brazil n=755; Canada n=755; United Kingdom n=755
 Q17. From the list below, which, if any, of the following statements describe why your emotional/mental health has worsened due the Coronavirus/COVID-19? Base:12-Country Total n=5557; Canada n=527; United States n=508; India n=353; Taiwan n=364; China n=386; United Kingdom n=531; Spain n=554; Australia n=428; Italy n=516; Brazil n=526



Carers' financial health suffers from additional spend on supplies and resources needed to provide care

54%

of carers say the pandemic has worsened their financial health

Even higher in **Brazil** (68%), **Spain** (62%) and **Italy** (60%).

Top Reasons among for worsening financial health during the pandemic (among carers whose financial health worsened)

| | More of my money is going toward supplies and resources I need to provide care | Government/social service/insurance provided financial support is not enough to cover my caregiving expenses | My professional/paid working hours were reduced/cut back. |
|---|--|--|---|
| Lowest to Highest relative to Global Average [^] | 49% China | 32% Taiwan | 30% China |
| | 48% Taiwan | 30% France | 28% Brazil |
| | 33% 12-country average | 25% 12-country average | 24% 12-country average |
| | 25% Spain | 19% Australia | 21% Germany |
| | 14% Italy | 16% China and United Kingdom each | 16% United Kingdom |

Across nearly all countries, carers' top contributor to worsening financial health is purchasing supplies and resources needed to provide care. Carers in **Brazil** (34%) and **China** (31%) are more likely to have experienced a reduction in their salary, compared to 23% of carers globally.

[^]Data demonstrates the countries that were highest and lowest in relation to the 12-country global average.
 Q12. In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: 12-Country Total n=9044; Brazil n=755; Spain n=751; Italy n=752
 Q20. Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due the Coronavirus/COVID-19? Base: 12-Country Total n=4901; China n=439; Taiwan n=338; Spain n=469; Italy n=449; France n=345; Australia n=392; United Kingdom n=407; Brazil n=510; Germany n=326



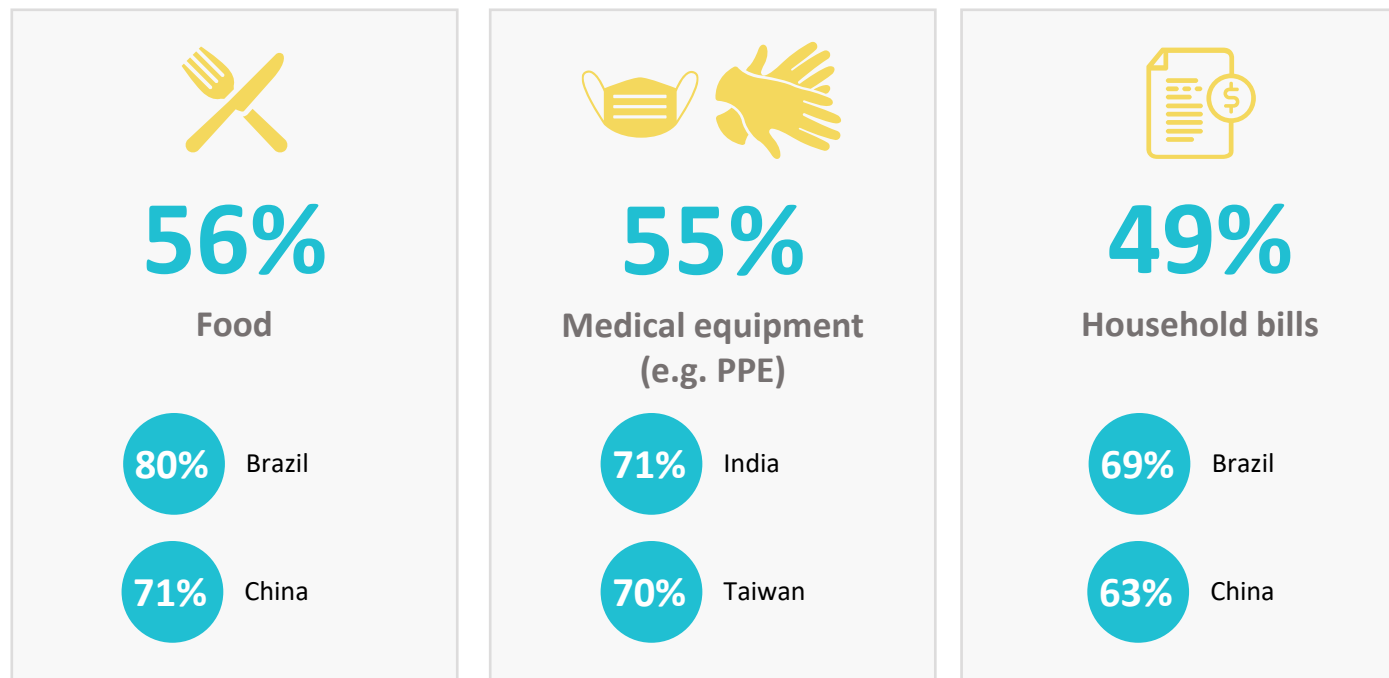
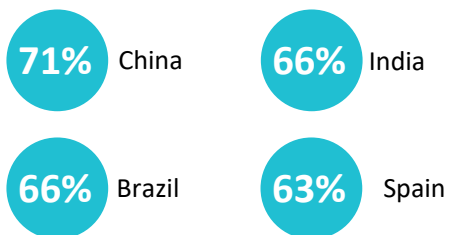
While carers believe their income will decrease during the pandemic, they are spending more money on key necessities

Top Items Carers are Spending More Money On Since the Beginning of the Pandemic:

56%

of carers believe their annual **household income will decrease** due to the pandemic

Carers in the countries below are more likely to believe their annual household income will decrease due to the pandemic:



Carers in the countries noted above are more likely to be spending more money on the following items, such as food, medical equipment, and household bills, since the beginning of the pandemic.



In addition to financial strain, carers' career prospects are deeply impacted, impeding their economic opportunity



22%

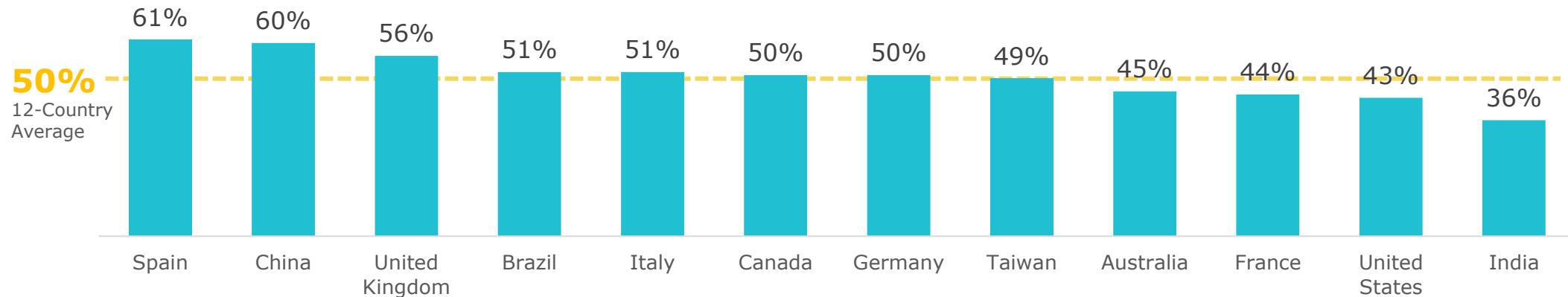
of carers, whose financial health has worsened due to the pandemic, say they've **had to reduce their professional/paid working hours because of their caregiving duties**

Compared to the 12-country average of 22%, carers in Taiwan and China are more likely to say their financial health worsened because they had to reduce their paid working hours for caregiving:

35% Taiwan

32% China

Percentage of carers who say being a carer negatively impacts their career



Carers from **Spain** (61%), **China** (60%) and the **United Kingdom** (56%) are significantly **more likely to believe being a carer negatively impacts their career**, while Indian (36%) and American (43%) carers are least likely to say so.

Q5. How, if at all, does being a carer/carer impact each of the following aspect of your life currently? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754
Q20. Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due the Coronavirus/COVID-19? Base: 12-Country Total n=4901; China n=439; Taiwan n=338





Lack of sleep and exercise adversely impact carers' physical health



Top Reasons among for worsening physical health during the pandemic (among carers whose physical health worsened)

46%

of carers say the pandemic has worsened their **physical health**

Higher in **Spain** (62%), **Brazil** (57%) as well as **Canada** and **Italy** (51% each).

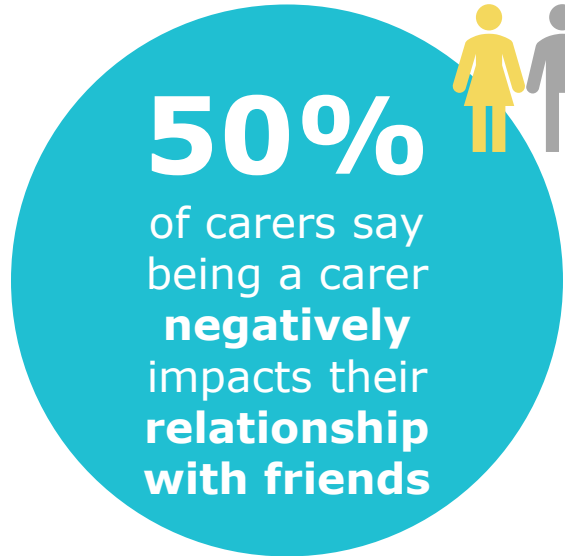
| | I am lacking sleep | I am exercising less | I have postponed my own medical appointments |
|---|-------------------------------|-------------------------------|--|
| Lowest to Highest relative to Global Average^ | 63% Spain | 56% Brazil | 45% United States |
| | 62% United States | 51% Spain | 42% Brazil |
| | 55% 12-country average | 45% 12-country average | 34% 12-country average |
| | 47% Germany | 36% France | 21% Taiwan |
| | 46% Italy | 30% Germany | 20% India |

In most countries surveyed, the top three reasons for their physical health worsening during the pandemic is due to lack of sleep, exercising less, and postponing medical appointments. Although, compared to the 12-country average, **carers in India** are struggling to access (32% vs. 12%) and afford (27% vs. 16%) nutritious food (e.g. fruits and vegetables, etc.).

^Data demonstrates the countries that were highest and lowest in relation to the 12-country global average.
Q12. In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: 12-Country Total n=9044; Spain n=751; Brazil n=755; Italy n=752; Canada n=755
Q19. Now, please select from the below list, which, if any, of the following statements describe why your physical health has worsened due the Coronavirus/COVID-19? Base: 12-Country Total n=4128; Spain n=467; United States n=327



5 Carers' social relationships are suffering; while peer connection can enhance emotional health, few are doing it



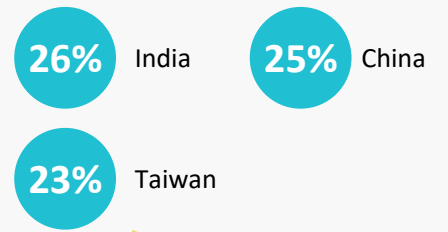
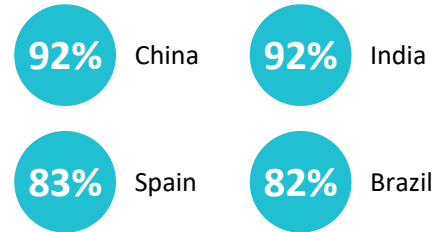
Higher in the **United Kingdom** (63%) and **Spain** (61%).

Although 76% say **connecting with other carers who are going through similar situations always makes them feel better**



Only 17% talk to other carers (online, in-person, or over the phone) as an activity to improve their emotional/mental health during the pandemic

Carers in the countries below are more likely to say connecting with other carers in similar situations always makes them feel better:



While peer connection is an effective way to improve mental health, few are talking to other carers. However, **carers in Asia lead the way in peer connection.**

Q5. How, if at all, does being a carer/carer impact each of the following aspect of your life currently? Base: 12-Country Total n=9044; United Kingdom n=755; Spain n=751
 Q18. Which, if any, of the following activities have you done since the Coronavirus/COVID-19 pandemic began to help improve your emotional/mental health? Base: 12-Country Total n=9044; China n=754; India n=750; Taiwan n=753
 Q24. To what extent, if at all, do you agree with each of the following statements: - Agree Summary Base: 12-Country Total n=9044 ; China n=754; India n=750; Spain n=751; Brazil n=755



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“The restrictions made it harder to know what I could or could not do. Also, **not being able to take her out and having to manage her anxiety and emotional distress made caregiving harder.**”

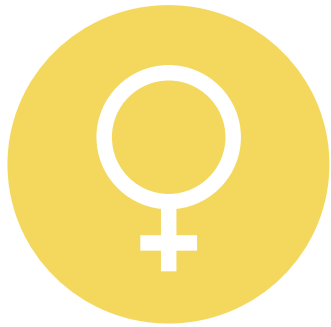
– 33-year-old Female from the United Kingdom taking care of someone with an ongoing mental condition

IV: Inequities Impacting Carers around the World

Carers aren't all alike—and circumstances, such as age, gender, and the disease types they care for, can present each person with unique challenges.

- **Female carers** are more likely to report emotional impacts and to wish for more mental and social support.
- **Younger carers** are hungry for guidance and peer connections.
- **Middle-aged carers** are more likely to be parents—and they're looking for financial support.
- **Older carers** feel the lack of support during the pandemic and have difficulty handling technology.
- Mental health is a deeper strain for carers who help people with **cancer**.

Around the globe, carer experiences are diverse and some groups face greater challenges than others



**Women
Carers**



**Young
Carers**



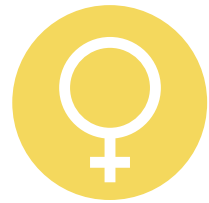
**Middle-
Aged
Carers**



**Older
Carers**

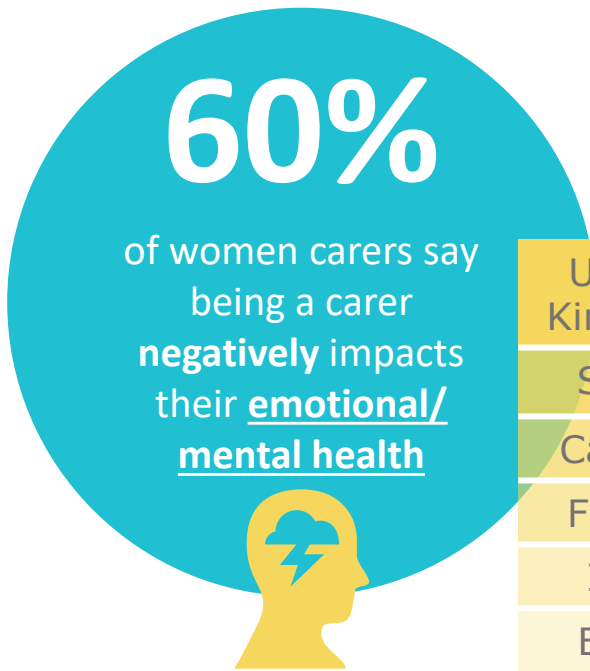


**Cancer
Carers**



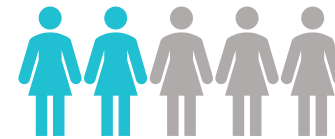
Women carers recognize the effect of caregiving on their emotional/mental health, heightened by the pandemic

While men still experience struggles, women disproportionately face greater emotional/mental health struggles than male carers. Three in five women carers say being a carer negatively impacts their emotional/mental health and the pandemic has only elevated the anxiety for they face themselves and the individual(s) they take care of.



(Men carers: 55%)

| | Women | Men |
|----------------|-------|-----|
| United Kingdom | 74% | 62% |
| Spain | 71% | 62% |
| Canada | 71% | 59% |
| France | 64% | 55% |
| Italy | 64% | 53% |
| Brazil | 56% | 41% |



41%
say uncertainty caused by the Coronavirus/ COVID-19 is causing anxiety for both/all of us

(Men carers: 37%)

| | Women | Men |
|----------------|-------|-----|
| Canada | 52% | 37% |
| United States | 49% | 34% |
| United Kingdom | 49% | 37% |
| Italy | 40% | 32% |

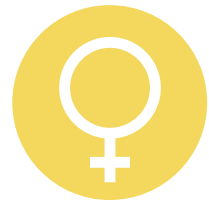
*References to women are specific to female carers, similarly men callouts are specific to male carers.

Q5. How, if at all, does being a carer/carer impact each of the following aspects of your life currently? - Negative Summary Base: Global Female n=5711; Global Male n=3323; United Kingdom Female n=492; United Kingdom Make n=261; Spain Female n=486; Spain Male n=265;

Canada Female n=463; Canada Male n=291; France Female n=454; France Male n=305; Italy Female n=496; Italy Male n=255; Brazil Female n=507; Brazil Male n=246

Q14. Which, if any, of the following statements is true for you as it relates to how the Coronavirus/COVID-19 pandemic has impacted your ability to provide care? Select all that apply. Base: Female n=5711; Male n=3323; Canada Female n=463; Canada Male n=291; United States

Female n=499; United States Male n=250; United Kingdom Female n=492; United Kingdom Make n=261; ; Italy Female n=496; Italy Male n=255



Women desire mental health resources and support from health and social services

Nevertheless, there is seemingly a disconnect between men's and women's support needs, with women carers more likely to desire greater mental health resources and support. Women carers in select countries, such as Brazil, are even more likely to want more mental health resources and support from health and social services.



54%

strongly agree that there needs to be more **mental/wellness resources** readily available for carers

(Men carers: 46%)



| | Women | Men |
|----------------|-------|-----|
| Brazil | 72% | 63% |
| Spain | 65% | 56% |
| United States | 57% | 46% |
| Canada | 52% | 43% |
| United Kingdom | 52% | 43% |
| China | 49% | 39% |
| Australia | 49% | 38% |



54%

strongly agree **health and social services/care system** needs to do more to support carers/carers

(Men carers: 49%)



| | Women | Men |
|----------------|-------|-----|
| Brazil | 71% | 62% |
| Germany | 59% | 49% |
| United Kingdom | 54% | 45% |
| United States | 54% | 44% |
| Canada | 54% | 44% |

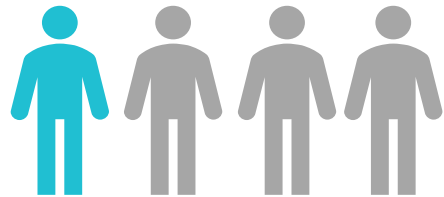
*References to women are specific to female carers, similarly men callouts are specific to male carers.

Q29. How much do you agree, if at all, with each of the following statements? Base: Female n=5711; Male n=3323; United Kingdom Female n=492; United Kingdom Make n=261; Canada Female n=463; Canada Male n=291; Brazil Female n=507; Brazil Male n=246; United States Female n=499; United States Male n=250; Spain Female n=486; Spain Male n=265; China Female n=463; China Male n=291; Australia Female n=506; Australia Male n=245; Germany Female n=451; Germany Make n=305



Young adults, as newer carers, seek guidance navigating services and crave connection with peers

One in four 18-34-year-olds became carers for the first time because of the pandemic and recognize they need assistance navigating the health and social services/care systems to ensure they are getting all the benefits they are entitled to.



26%

of 18-34-year-old carers became first-time carers **because of the pandemic**

(Total Carers: 20%)

95%

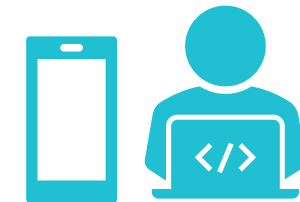
of 18-34-year-old carers believe “help navigating the health and social services/care systems to ensure I am getting all the benefits I am entitled to” is important to ensure they are providing proper care needed

(Total Carers: 93%)

88%

of 18-34-year-old carers say **ways to connect with other carers (e.g. social media and online forums)** is important to ensure they are able to provide the care needed

(Total Carers: 82%)



81%

say **connecting with other carers** who are going through similar situations always makes me feel better

(Total Carers: 76%)



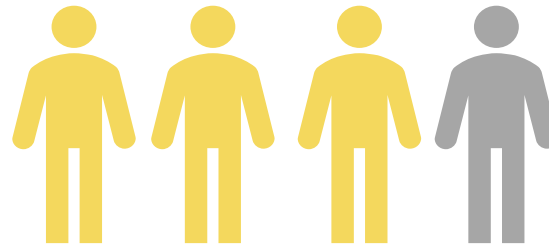
Sandwiched by parenting and caregiving strains, middle-aged carers are in dire need of greater support

Most (67%) 35-54-year-olds carers surveyed are parents in addition to carers. The demands of caring for both groups has placed financial strain on them, as the majority (75%) are concerned they are not going to be able to afford to provide proper care. Even more, half of middle-aged carers find support from the federal governments to be very important and two in five strongly agree insurance organizations should do more to support them.

67%

of 35-54-year-old carers are **parents**[^]

(Total Carers: 52%)



75%

of 35-54-year-old carers are **concerned they are not going to be able to afford** to provide proper care

(Total Carers: 71%)



52%

of 35-54-year-old carers say more financial tools to support unpaid carers from the **federal government** is *very important*

(Total Carers: 50%)



41%

of 35-54-year-old carers strongly agree that **insurance organizations** (e.g. care insurance and SHI, health insurance) should do more to support me as a carer

(Total Carers: 37%)

[^]References to parents are specific to parents and/or full-time guardians of any children under the age of 18 in their household

S15. Are you the parent or full-time guardian of any children under the age of 18 in your household? Base: 12-Country Total n=9044; 35-54 n=4342

Q24. To what extent, if at all, do you agree with each of the following statements: - Agree Summary Base: 12-Country Total n=9044; 35-54 n=4342

Q26. How concerned are you, if at all, about each of the following as it relates to caregiving? - Concerned Summary Base: 12-Country Total n=9044; 35-54 n=4342

Q28. As you continue to be a carer, how important will each of the following items be in ensuring you are able to properly provide the care needed? - Important Summary Base: 12-Country Total n=9044; 35-54 n=4342



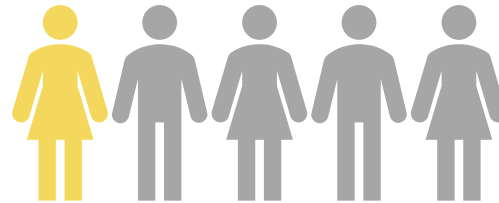
Older carers largely feel unsupported and desire further support in addressing technology gaps and barriers

55+ year-old carers have less opportunities to access their support systems and services in comparison to carers globally. Even more so, two thirds report not receiving enough support from government institutions and one in five do not feel comfortable using technology to care for their loved one(s).

One in three

55+ year-old (31%) carers say they have had less opportunities to access support systems (e.g. friends, family, etc.) and services (e.g. activities, group sessions, etc.) during the pandemic

(Total Carers: 28%)

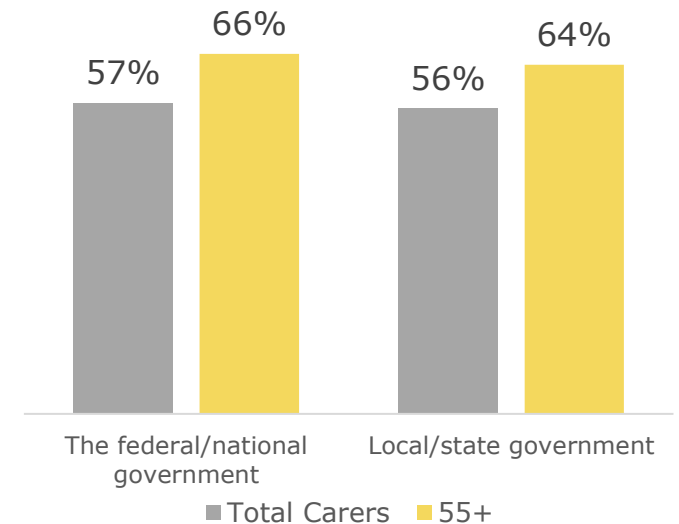


21%

of 55+ year-old carers say they do not feel comfortable using technology to care for their loved one (e.g. telehealth, online tools and mobile apps)

(Total Carers: 13%)

Carers report not receiving enough support from:





Carers of those with cancer are just as hurt by a lack of a support, and bear unequivocal mental health struggles

Carers of people with cancer have unique mental health struggles, and a lack of financial or other support exacerbates their negative experiences as carers.



66%

of Cancer carers say being a carer has had a negative impact on my emotional/mental health

(Total carers: 58%)



71%

Of Cancer carers say the COVID-19 pandemic has made caregiving harder

(Total carers: 64%)

Carers for a person with cancer have never received support, financial or otherwise, from:

| | | |
|---|----------------|----------------------------------|
| Private companies | 84% vs. | 79% 12-country average |
| Non-profit organizations/ advocacy groups | 77% vs. | 72% 12-country average |
| Insurance organizations | 71% vs. | 67% 12-country average |
| The local/ state government | 73% vs. | 68% 12-country average |
| Local communities | 73% vs. | 67% 12-country average |



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V: Path to Solutions

As pressure grows on carers, they need to receive more support so they can keep on giving it. The global community can help in a number of distinct ways.

- Majority of carers are concerned about increased COVID-19 infections from the **second wave** and **re-openings**.
- From food to equipment to technology carers have identifiable, **unmet needs**.
- Juggling caring with **work** is a challenge employers are positioned to help address.
- Carers say they feel invisible—and would welcome **recognition and support** from public, private, and social institutions.
- Closing these gaps in **resources and support** will take tangible measures from multiple players at once.

“ See us. Hear us. **Care about our stories and our pain.** ”

– 36-year-old female from United States taking care of someone with an ongoing/long-term cognitive/mental condition

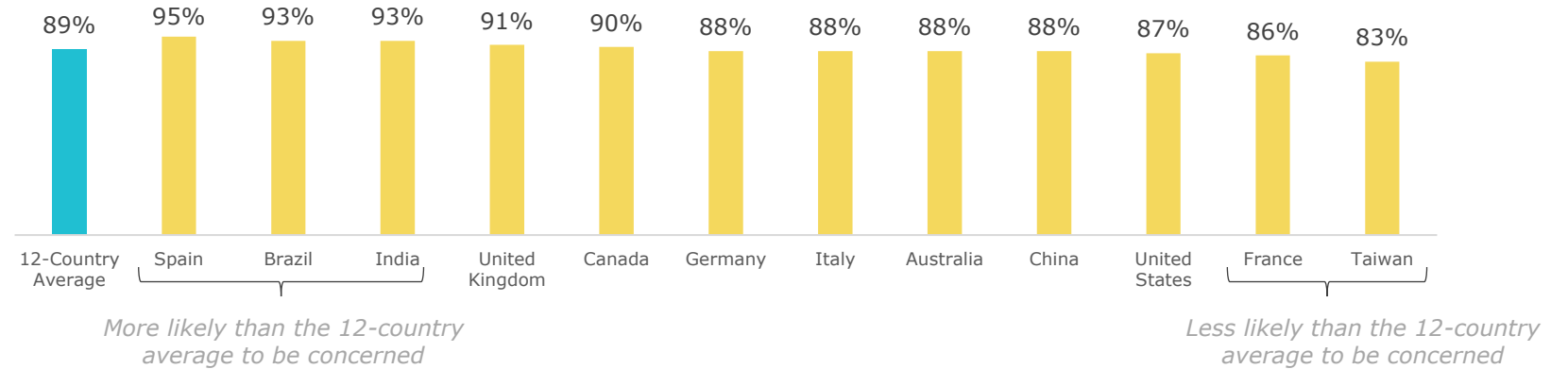
Hasty re-openings and infection risks trouble carers at large, with carers in Spain, Brazil and India experiencing the most concern on these issues

Top concerns for carers:

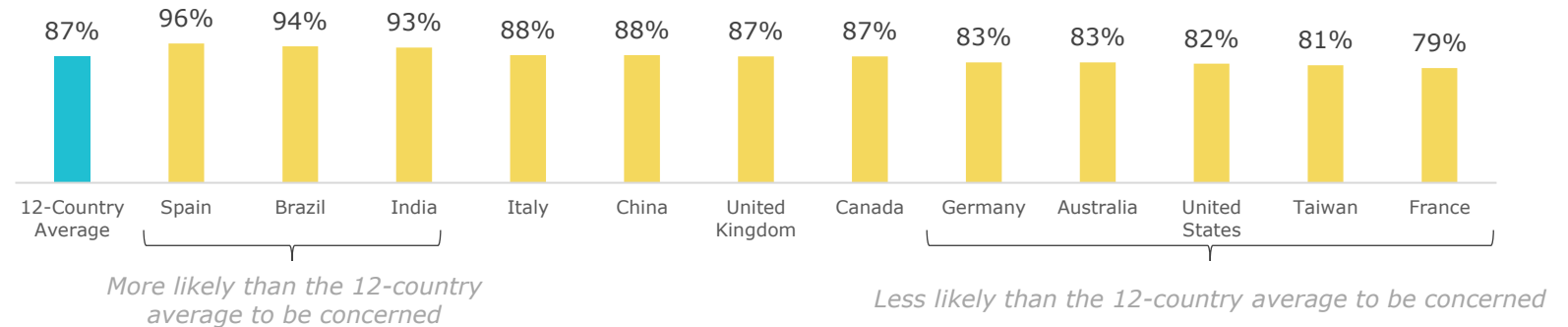
Carers across the 12-countries surveyed are generally concerned for an increase in COVID-19 infections, with levels of concern heightened in Spain, Brazil and India.

How to protect the person(s) they care for is a heavy burden carers carry.

The second wave of the Coronavirus/COVID-19 in general



Increase in Coronavirus/COVID-19 infections from re-openings



Q26. How concerned are you, if at all, about each of the following as it relates to caregiving? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Concerns regarding access, employment and technology follow pressing infection threats



Access & Affordability

71%

I am concerned that I will not be able to **afford to provide** proper care

More likely to be concerned: Carers in India (85%), Brazil (82%), China (82%), and Spain (77%)

68%

Lack of access (to PPE, medication, food, etc.) generally is among the biggest challenges I face during the COVID-19 pandemic

More likely to be a top challenge: Carers in India (77%), Italy (74%), Brazil (73%), and China (73%)



Employment Pressures

72%

I am concerned that I will have to **work full time remotely** while also caregiving for the foreseeable future

More likely to be concerned: Carers in India (91%), Brazil (80%), China (79%), and Spain (76%)

21%

Difficulty **juggling my paid job/career and being a carer** is among the biggest challenges carers face during the COVID-19 pandemic

More likely to be a top challenge: Carers in Brazil (26%)



Technology Demands

61%

I am concerned that I will need to use **more technology and digital tools** to manage care properly

More likely to be concerned: Carers in India (86%), China (80%), and Brazil (65%)

37%

I am spending more money on technology needed to be a caregiver, since the COVID-19 pandemic began

More likely to spend money: Carers in India (58%), China (56%), Taiwan (51%)

Invisible and unsupported, carers at a global level lack support systems and recognition

Carers feel invisible, reporting in near unison that their contributions are not recognized. Too little support from government, the private sector and the communities they live in contribute to this point of view.



94%

agree the important role carers have is **not widely recognized by society**

Carers who do not feel they are receiving enough support from.....

| | | |
|-------------------------------------|------------|-----------|
| Federal/national government | 57% | 63% Spain |
| Local & state/province government | 56% | 64% Spain |
| Private companies | 52% | 59% Spain |
| Insurance organizations | 51% | 61% Spain |
| Social services/ care professionals | 51% | 64% Spain |
| Local communities | 50% | 64% Spain |

Carers in Spain are more likely than the 12-country average to feel they are not receiving enough support from any of the above entities – they are 14 points more likely to say local communities need to lend further support.

Public and private entities around the globe play a critical role in supporting carers, particularly employers and social services

As the pandemic endures, carers are seeking increased support from health and social services, as well as employers. Differences in the level of services and engagement currently offered by each nation across the 12-countries surveyed exist. For instance, Canada and the United Kingdom offer universal healthcare to citizens, however the vast majority are still seeking more involvement.

*To close the resource gap, a variety of **public and private actors will need to offer concrete support for carers. No one entity bears the weight alone.***

To support carers:

The health and social services/ care system needs to do more



Employers should provide additional flexibility policies





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Conclusion & Opportunities



Cassie Day (carer) and her son Matthew

Key regions around the globe experience their own unique caregiving hurdles



AMERICAS

(Brazil, Canada, U.S.A.)

- **U.S. carers (77%) say providing emotional support is a top responsibility**, a higher incidence than the 12-country average (65%).
- More than other countries, **Brazilian carers experienced a surge in emotional support responsibilities** (65% vs 57%, 12-country average), **greater demand in managing technology*** for telehealth (64% vs 51%, 12-country average), and **elevated homecare responsibilities**** as a result of the pandemic (66% vs 45%, 12-country average).
- Compared to carers in the other countries surveyed, **U.S. carers face heightened demand to manage technology*** (67% vs. 51%, 12-country average).



EUROPE

(U.K., France, Germany, Italy, Spain)

- **Spanish carers** are more likely to **experience caregiving's negative impact on their social friend relationships and career (61% each)**, compared to the 12-country average (50% each). **Spanish carers are more likely to feel unsupported** by local/state governments (64% vs 56%, 12-country average), social services (64% vs 51%, 12-country average), and local communities (64% vs 50%, 12-country average) and insurance organizations (61% vs 51%, 12-country average).
- **British carers** (63%) are significantly more likely than the 12-country average (50%) to **believe being a carer negatively impacts their relationship with their friends**.
- **Carers in Italy** (65%) are more likely than the 12-country average (57%) to **feel unsupported by their federal/national government**.



ASIA-PACIFIC

(India, China, Taiwan, Australia)

- **Carers in India (26%), China (25%) and Taiwan (23%) lead in leveraging peer connection** with other carers as an effective way to improve mental health during the pandemic (vs. 17%, 12-country average).
- **Carers in Asia** (39% of those in India, 34% in China and 31% in Taiwan) were more likely than the 12-country average (20%) to have **become first time carers as a result of the pandemic**. Carers in those countries experienced the greatest resultant surge in the time needed to provide care, above the other countries surveyed (9+ hours/week per each Asian country, vs. 6+ hours/week 12-country average). Today, carers in Asia experience less appreciation from the individual(s) they care for (32% China, 30% India, and 29% Taiwan) compared to carers in the other countries surveyed (38%, 12-country average).
- **Carers in Taiwan** whose emotional/mental health worsened as a result of the pandemic are **more likely to feel anxious about balancing their paid job/work and caregiving responsibilities** (39% vs. 29%, 12-country average).
- More than carers in the other countries surveyed, **Indian carers are concerned about not having enough money to pay for everything they need for the individual(s) they care for** (85% vs. 71%, 12-country average).
- Carers in China (94%), Taiwan (91%), and India (85%) are among the most likely to **desire greater guidance on telehealth technologies** to provide care (vs. 68%, 12-country average).
- **Carers in China** whose financial health worsened are **more likely to have experienced a salary reduction as a result of the pandemic (31%)**, compared to 23% of carers across the 12 countries surveyed.

*Managing technology NET consists of the total respondents who chose 'managing the technology needed for telemedicine/telehealth/virtual medical appointments' and/or 'managing the technology needed for the person(s) to keep in touch with loved ones' as top responsibilities that have increased due to the pandemic.

**Homecare NET consists of total respondents who chose either 'home maintenance and/or housekeeping' and/or 'personal hygiene' as top responsibilities that have increased due to the pandemic.

The global pandemic has had a dramatic impact on carers around the world



Rising Demands

In every nation surveyed, the pandemic is requiring carers to do more. And these demands will continue, long after the pandemic is addressed.



Changed Responsibilities

While the nature of new expectations on carers vary around the world, they need urgent support to navigate and address the new challenges they face.



The Toll on Carers

Carers around the globe are feeling overwhelmed, facing burnout that is aggravated by financial strains and growing fears of the lasting impact of the pandemic. They require tools and resources to survive and thrive.



Inequities Impacting Carers around the World

The pandemic has exacerbated the challenges facing women carers and others. Specific steps must be taken to address these imbalances.



Path to Solutions

Each country must ensure carers receive early and continuing support to emerge safely - and as soon as possible - from the grip of the pandemic. Across public and private sectors, everyone has a role to play.

Carer Advocacy Priorities



The Carer Well-Being Index serves as a resource with insights and solutions to help the public and private sector better support unpaid carers around the world.

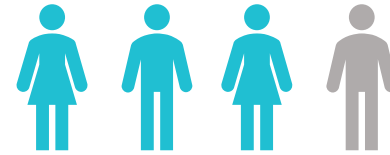
Embracing Carers, along with its partners, has recognized five advocacy priorities that address universal needs for unpaid carers. These priorities form the framework for recommended actions – by governments, civic organizations, employers and communities – highlighted by the results of the *Global Carer Well-Being Index*.

Global Carer Priorities

- Safeguard the health and well-being of unpaid carers.
- Minimize the financial burden placed on unpaid carers.
- Enable access to user friendly information and education.
- Support unpaid carers who are employed.
- Invest in research to ensure carers' needs and contributions are recognized and addressed.

1. Safeguard the health and well-being of unpaid carers

- Ensure unpaid carers receive the earliest possible access to COVID-19 vaccines
- Provide access to and distribute (PPE) to carers at a reduced or minimal cost
- Create effective and widely-available carer support networks to enhance and formalize local connections between carers to support carer mental health
- Develop and implement accessible training for new and long-term carers (and those who support carers) in managing stress and avoiding burnout
- Offer no-cost counseling programs to assist carers in coping with stress and challenges associated with caregiving
- Policymakers must recognize unpaid carers as a vital part of the healthcare workforce and provide appropriate protections for the safety of carers and the individual(s) they care for



Three fourths (76%) of carers have felt more burnt out than ever caring for someone during the pandemic



Caregiving has had a negative impact on carers' emotional/mental health (58%)



Carers say connecting with other carers going through similar situations always makes them feel better (76%)



Access to masks, gloves and other PPE is important to carers in ensuring they can properly provide the care needed (94%)

2. Minimize the financial burden placed on unpaid carers

- Develop and improve policies and programs to provide effective government support to address the direct and indirect costs associated with caregiving
- Ensure employed carers are granted time off to support family members needing care
- Ensure carers can access affordable transportation, groceries and meal services
- Develop and ensure access to respite programs to provide low/no cost short term accommodation for the person being cared for

Primary Responsibilities as a Carer Include

56%
Preparing meals

55%
Home maintenance and housekeeping

54%
Transportation

94% 

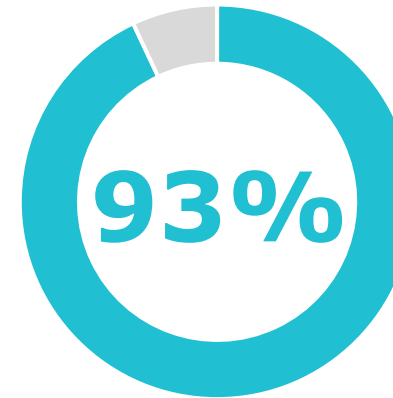
Almost all carers say financial tools to support them from the national government is important for them to properly provide care needed



Two thirds (66%) of employed carers* say their employer does not support them in ways they need to be a carer

3. Enable access to user friendly information and education

- Provide and support training on access to and effective use of evolving telehealth resources
- Assist the growing population of first-time carers through education and support
- In underserved communities, ensure carers have access to high-speed internet connections and the hardware necessary to access care remotely
- Ensure hospitals/nursing homes and other settings provide support systems for carers to ensure access to care and carer well-being
- Develop a universal carer identification card (or “carer passport”) to ease carers’ ability to act on behalf of persons for whom they are caring for and to ensure quick access to training and information to support caregiving



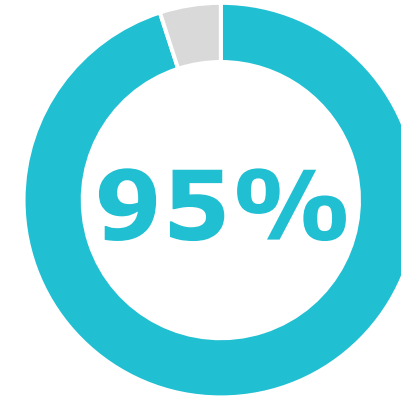
of carers say **help navigating the health and social services/care system to ensure they are getting all the benefits they are entitled to is important** to properly providing the care needed



Two thirds (68%) of carers agree they need additional guidance/training on how to use telehealth/online tools/mobile apps for caregiving

4. Support unpaid carers who are employed

- Create flexible workplace and educational environments that respect caregiving obligations
- Develop employer and employee support programs to create a culture that provides flexibility in working hours and settings by recognizing the unpredictable nature of caregiving, including standards and benchmarking
- Create national policies to incentivize employers to actively support unpaid carers
- Improve carer and employer access to information to ensure unpaid carers effectively make use of all government-sponsored and private-sector support and resources



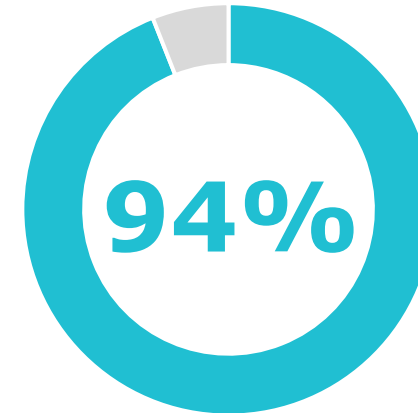
of carers say
**employers should
provide additional
flexibility policies
and support** for
carers



Nine in ten (89%) carers say carer-friendly workplaces that understand and respond to their needs as a carer is important in ensuring they can properly provide care needed

5. Invest in research to ensure carers' needs and contributions are recognized and addressed

- Support substantial investment in research by World Health Organization (WHO), the United Nations, International Labour Organization (ILO), World Bank, and other global agencies to understand how best to support and recognize carers around the world
- Urge non-governmental organizations (NGOs) to develop and underwrite research focused specifically on improving the lives of carers globally
- Develop research to better understand disparities faced by various carer populations (gender, race, age, etc.) and develop recommendations regarding how best to address them



of carers say **the important role they play is not widely recognized** by society



As a result of the pandemic, three fourths (75%) of carers are optimistic carers will get the support they have needed for a long time

The march forward in supporting carers

When the pandemic hit, the entire world was impacted. Countless countries shuttered their borders, businesses and families found themselves under stay-at-home mandates and quarantine orders. These new pressures made the care journey more challenging, both for carers living with someone in their care and those caring from a distance. Younger adults and parents were especially likely to step into caregiving roles, despite having to manage their own, interrupted obligations.

Carers haven't been alone in experiencing the pressures of the pandemic but many face pressures, demands and time commitments that others may not understand. As health and social care providers move to rapid responses to control COVID-19, carers must navigate fast-changing care delivery models, learn new telehealth and technology, provide emotional support despite their own emotional needs, and handle increased responsibilities at home—all at once.

The question remains: Who is caring for the carer? The carers in this survey reported that they often sacrifice their own health and well-being for the sake of people they love. They deal with emotional isolation. Financial strife hits hard as unemployment spikes and salaries are imperiled. Many lack the time to care for their own physical and emotional health. There are even more nuanced challenges when looking at women carers, younger, middle-aged and older carers, who encounter inequities, such as financial strain, lack of mental health support and more. In taking a hard look at how the pandemic has affected the globe, carers have faced unprecedented challenges – they are undercounted, unheard and struggling.

The question ahead, is **what are we going to do about it?** Now more than ever, federal and state governments, public entities, the private sector and all citizens of the globe have a role to play in addressing that problem. In moving forward, **carers should not have to face these hardships and inequities alone. As a society, we can help them, together.**

Resources & Acknowledgments

To learn more about caregiving and resources available for carers, as well as those advocating for carers, please visit our partner organizations' websites.

Embracing Carers' success comes through a collaborative effort by many. Thank you to the Embracing Carers partner organizations for their continued support and counsel on the 2020 Carer Well-Being Index. The completion of this research would not have been accomplished without the support of:





embracing
carers

Appendix

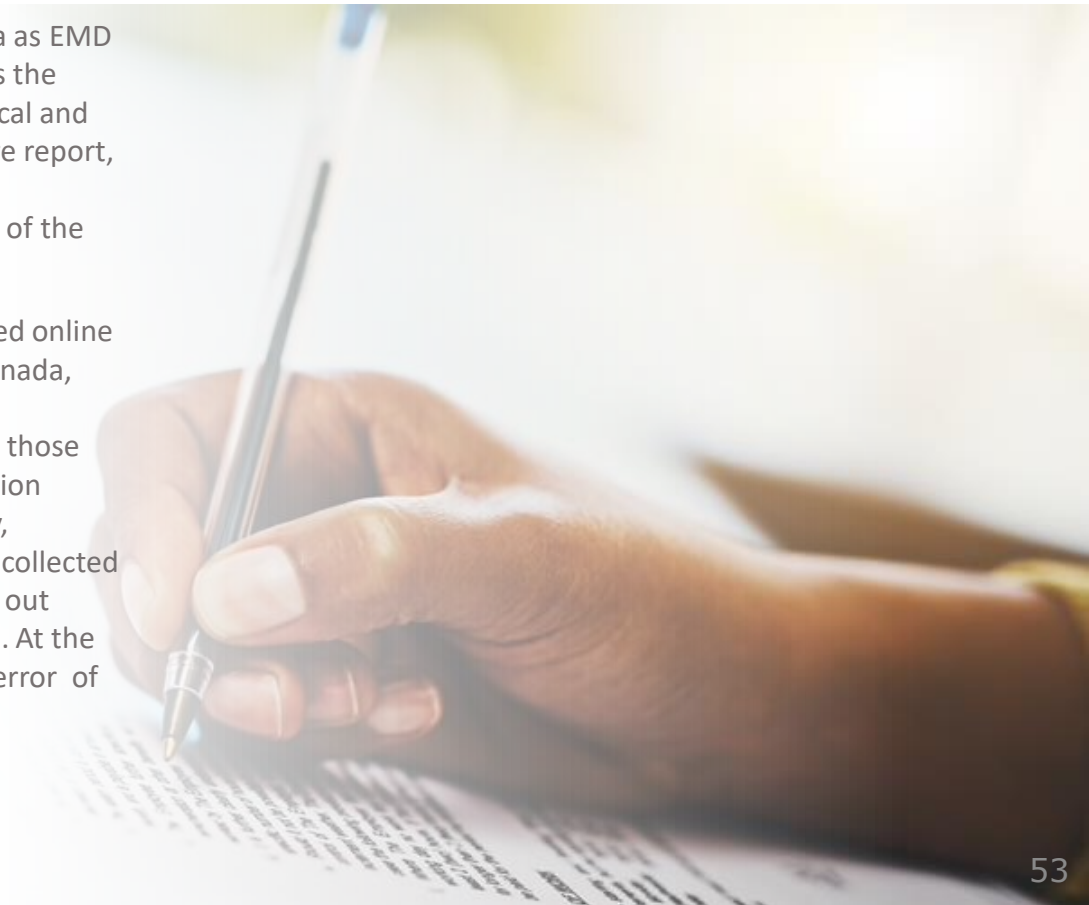


Vito Capozzo (carer) and his mother

Detailed research methodology

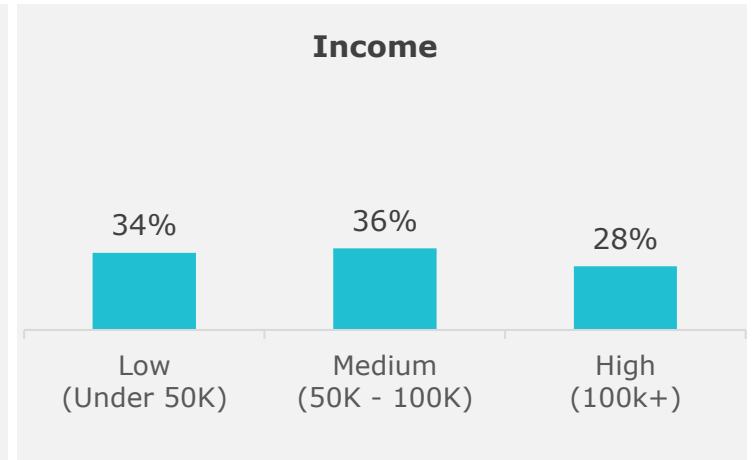
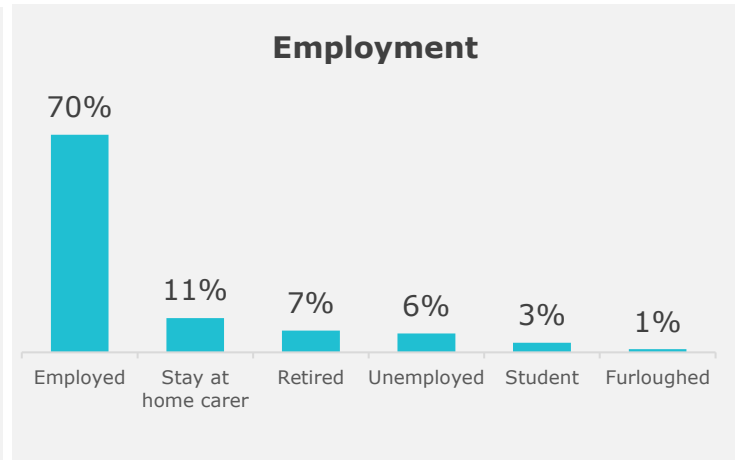
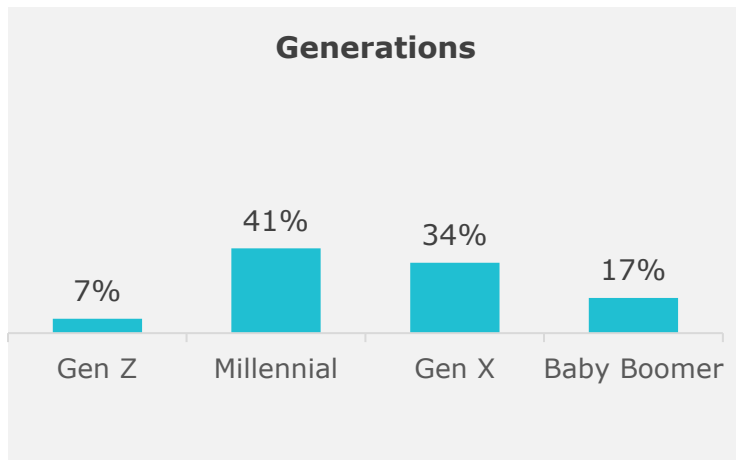
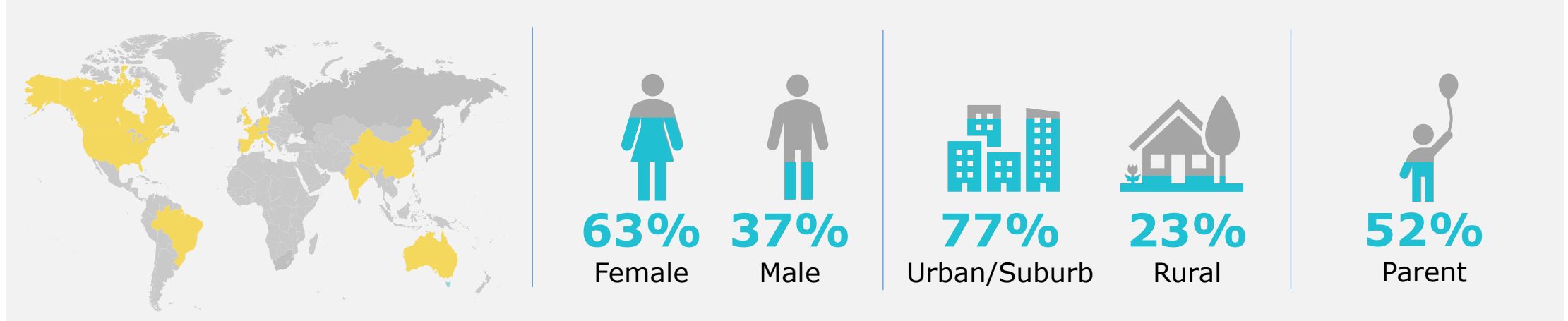
Merck KGaA, Darmstadt, Germany (operates its biopharmaceutical business in the U.S. and Canada as EMD Serono) has conducted proprietary research to determine the adverse and disproportionate affects the Coronavirus pandemic has had on unpaid carers around the world, including their economic, physical and psychological well-being. Building on the five global priorities established in the Global State of Care report, Merck KGaA, Darmstadt Germany/EMD Serono and its Embracing Carers partner organizations commissioned this research to give a clear mandate to leaders within the public and private sector of the concerns of unpaid carers and key solutions to best support them.

In partnership with a third-party global leader in multinational market research, a survey was fielded online from September 3 – October 27, 2020 across 12 countries, of which included the United States, Canada, United Kingdom, France, Germany, Italy, Spain, Australia, Brazil, Taiwan, India and China. The study consisted of 9,044 unpaid carers (n=750 in each country surveyed). Unpaid carers were defined as those who are caring for someone with a long-term illness, physical disability, or cognitive/mental condition (including cancer, Multiple Sclerosis, Parkinson's Disease, Dementia, Alzheimer's, Spinal cord injury, Muscular Dystrophy, cognitive/mental condition, Congestive Heart Failure, etc.). Outgoing sample collected was balanced to the Census of each respective country to then allow qualifying respondents to fall out naturally. Light weighting was applied in select countries to achieve better national representation. At the 95% confidence level, the total for the unpaid global carer population has an estimated margin of error of +/- 1.03 percentage points. The survey length was approximately 20-25 minutes.



Demographic breakout

Demographic breakout of sample (n=9,044)

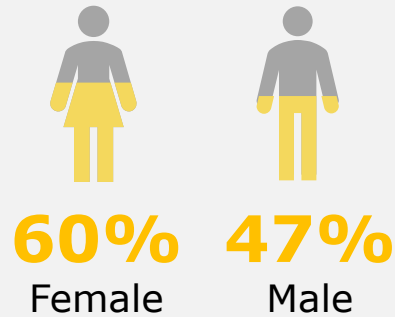


References to parents are specific to parents and/or full-time guardians of any children under the age of 18 in their household

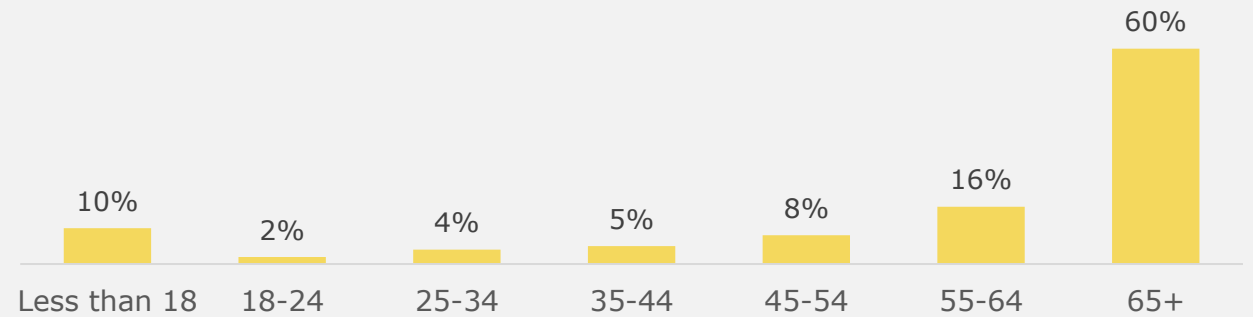
Detailed breakdown of conditions and people(s) being cared for

About the people they care for (n=9,044)

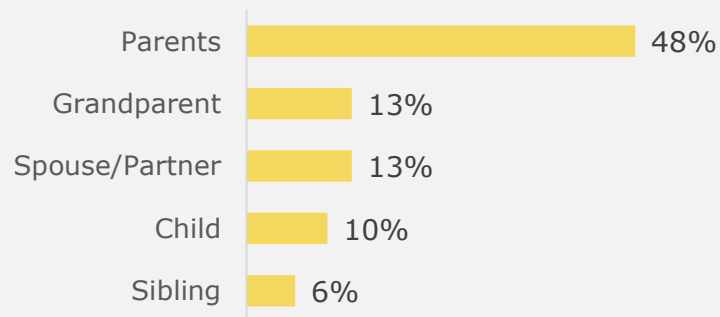
Gender of the person(s) they care for*



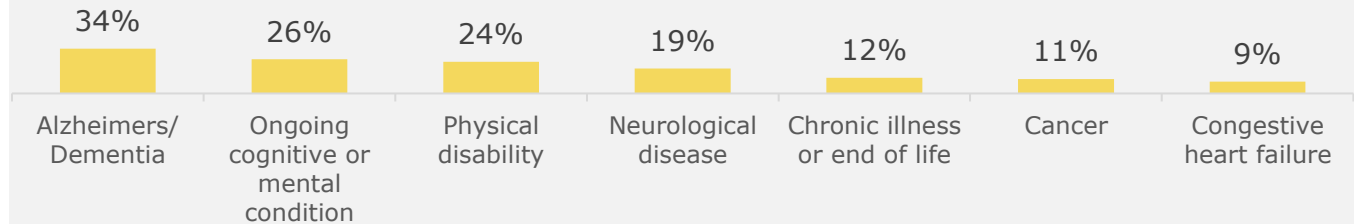
Age of the person(s) they care for*



Top relationships with the person(s) they care for



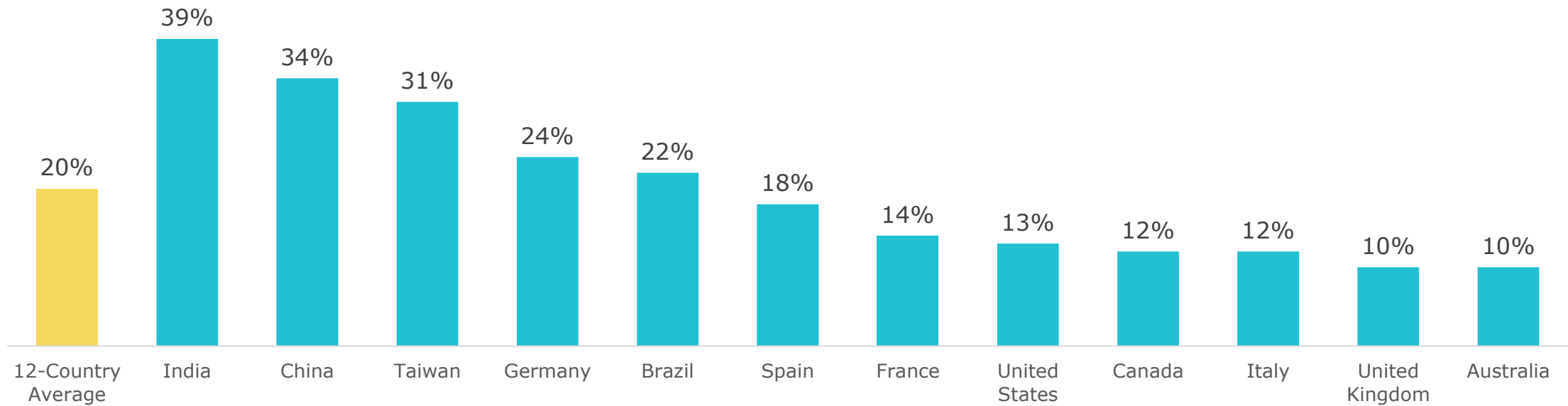
Conditions of the individual(s) they care for*



*May add up to more than 100% as carers could be looking after more than 1 individual

Rising Demands

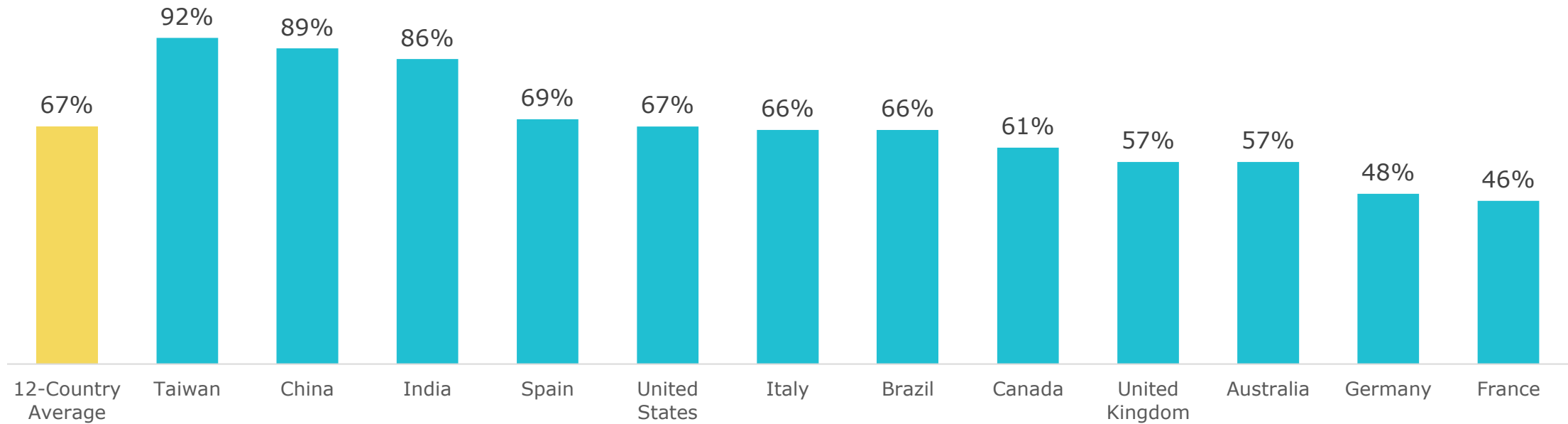
Became a caregiver/carer for the first time as a result of the Coronavirus/COVID-19 pandemic



Q7. Did you become a carer/carer for the first time as a result of the Coronavirus/COVID-19 pandemic? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

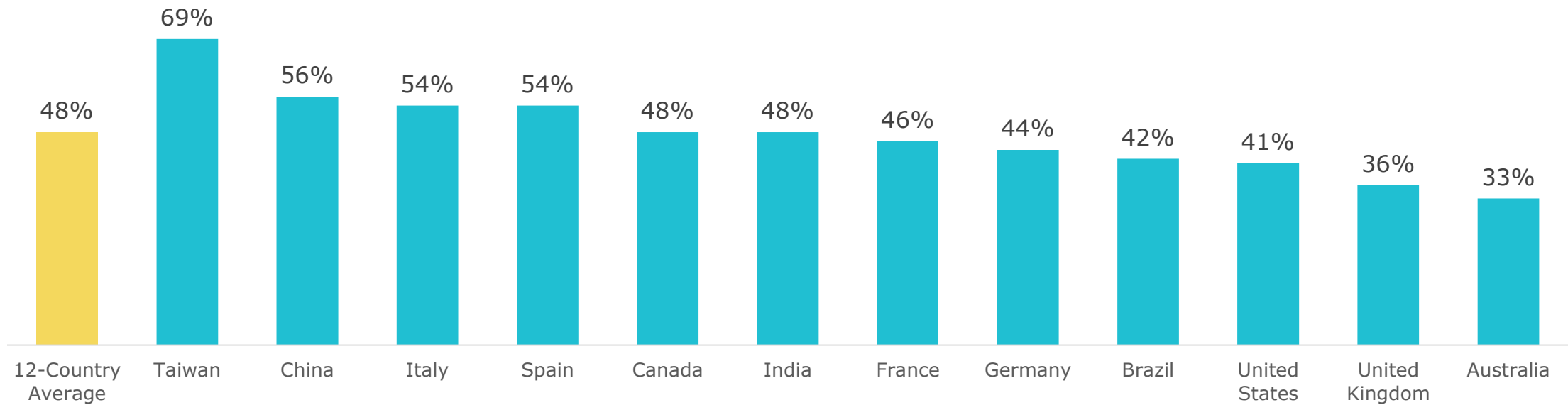
Rising Demands

Those who are a primary unpaid carer for someone inside their household/living with them



Rising Demands

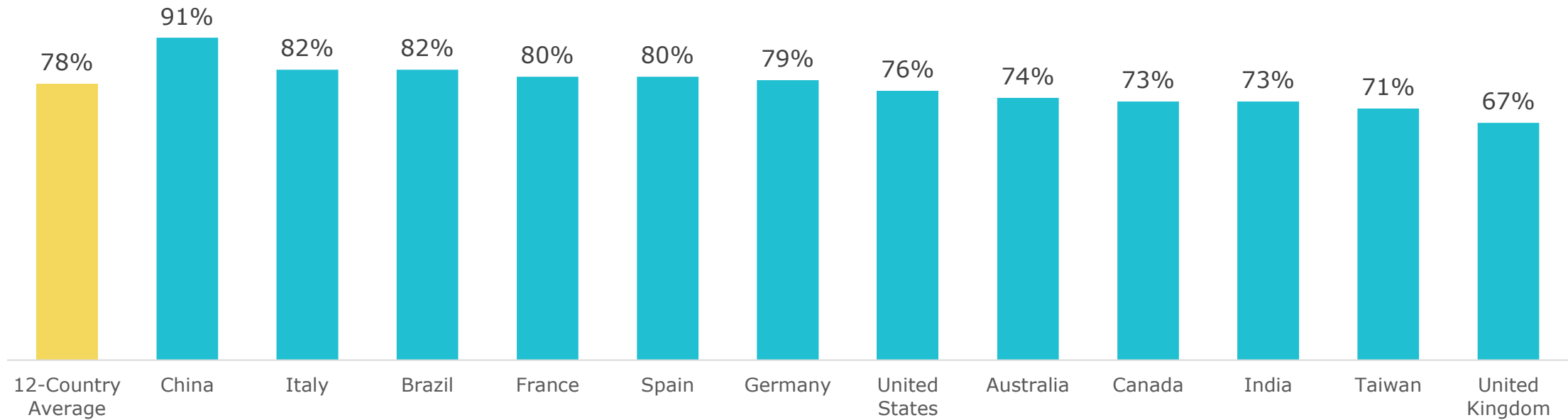
Those who are caring for a parent



Q3. Who is the ... year old ... you are caring for? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Rising Demands

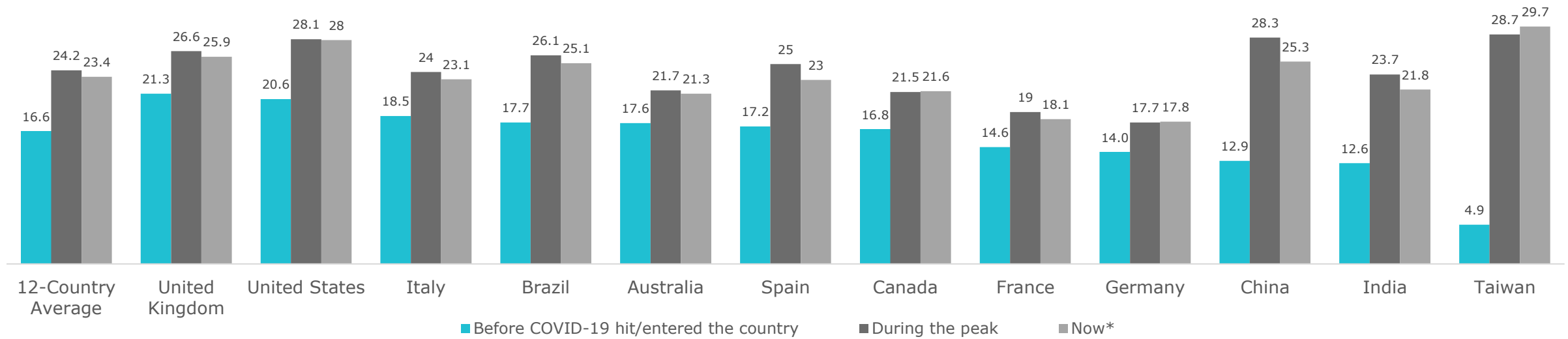
Those who have been a carer for five years or less



Q4. How long have you been a carer/carer? NET: Five years or less. Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Rising Demands

Average hours Carers spend on caregiving (per week)



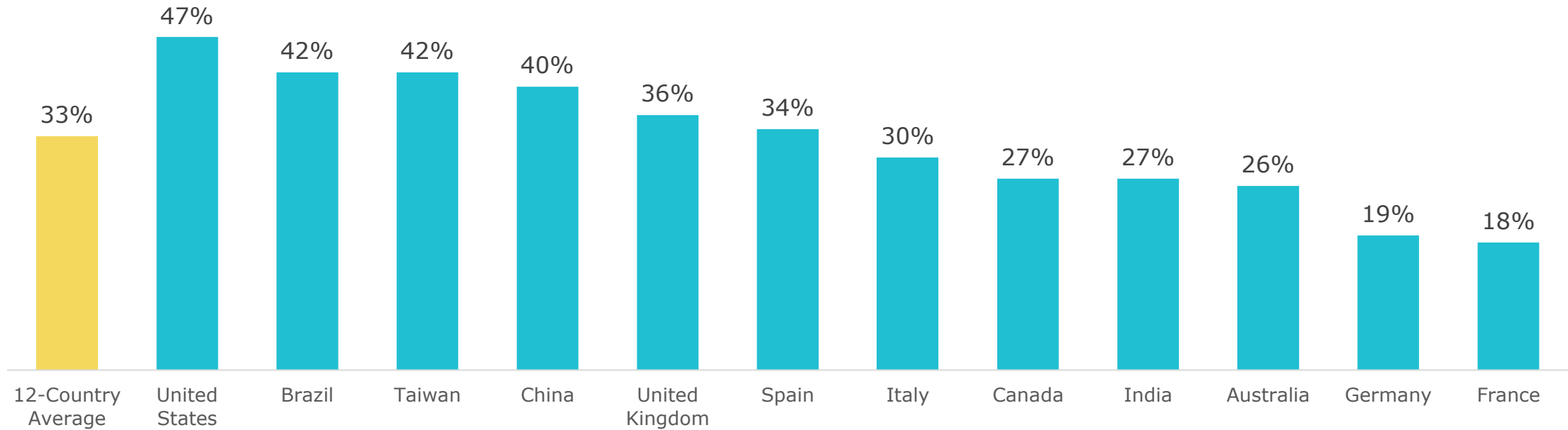
*Now refers to Fall 2020 when the survey was fielded

Q8. On average, how many hours did/do you spend per week on caregiving during each of the following timeframes? Please provide your best estimates. Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Embracing Carers™ is supported by EMD Serono

Rising Demands

Those who believe they will be spending, on average, 31+ hours a week on caregiving in the future due to the impact of the coronavirus



Q25. On average, how many hours do you think you'll be spending per week on caregiving in the future due to the impact of the Coronavirus/COVID-19 pandemic? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

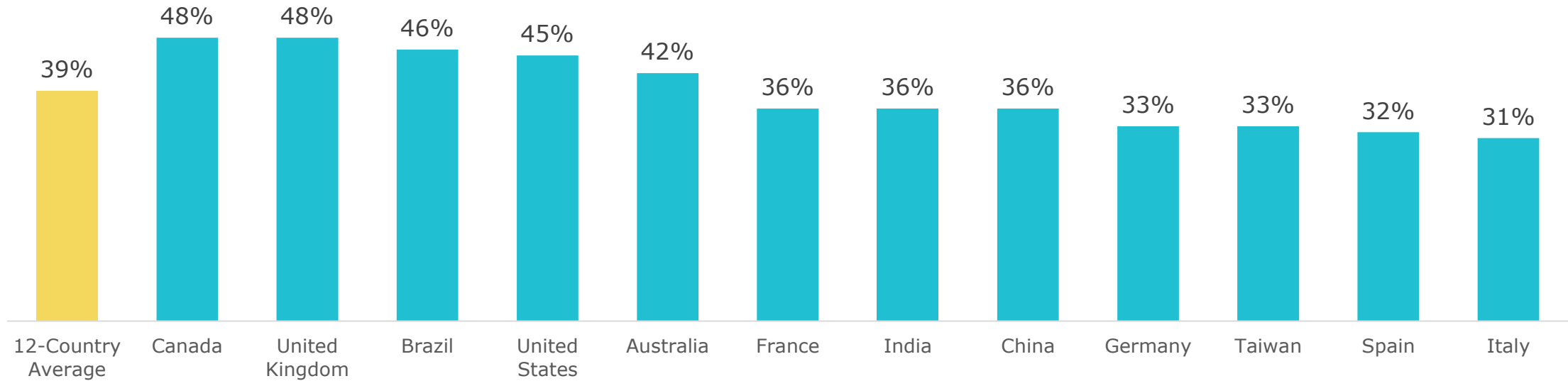
Rising Demands

Top responsibilities as a carer

| Responsibility | 12-Country Average | United States | Canada | United Kingdom | France | Germany | Italy | Spain | Australia | Brazil | Taiwan | India | China |
|-----------------------------------|--------------------|---------------|--------|----------------|--------|---------|-------|-------|-----------|--------|--------|-------|-------|
| Providing emotional support | 65% | 77% | 72% | 73% | 69% | 63% | 62% | 72% | 63% | 71% | 55% | 51% | 51% |
| Managing doctors appointments | 57% | 67% | 64% | 62% | 60% | 51% | 59% | 65% | 56% | 63% | 54% | 52% | 31% |
| Preparing meals | 56% | 70% | 63% | 66% | 53% | 49% | 52% | 66% | 57% | 60% | 38% | 43% | 58% |
| Home maintenance and housekeeping | 55% | 67% | 64% | 65% | 58% | 53% | 53% | 62% | 58% | 58% | 51% | 46% | 30% |
| Transportation | 54% | 68% | 63% | 56% | 60% | 51% | 53% | 59% | 58% | 56% | 48% | 37% | 32% |
| Giving/managing medications | 53% | 59% | 48% | 53% | 49% | 39% | 55% | 65% | 44% | 63% | 48% | 64% | 47% |
| Helping with personal hygiene | 46% | 51% | 35% | 47% | 39% | 39% | 46% | 54% | 34% | 51% | 48% | 49% | 55% |
| Helping with mobility | 43% | 47% | 37% | 45% | 36% | 33% | 47% | 57% | 31% | 51% | 41% | 50% | 41% |
| Managing their finances | 41% | 50% | 50% | 46% | 45% | 40% | 43% | 40% | 42% | 45% | 37% | 27% | 23% |

Rising Demands

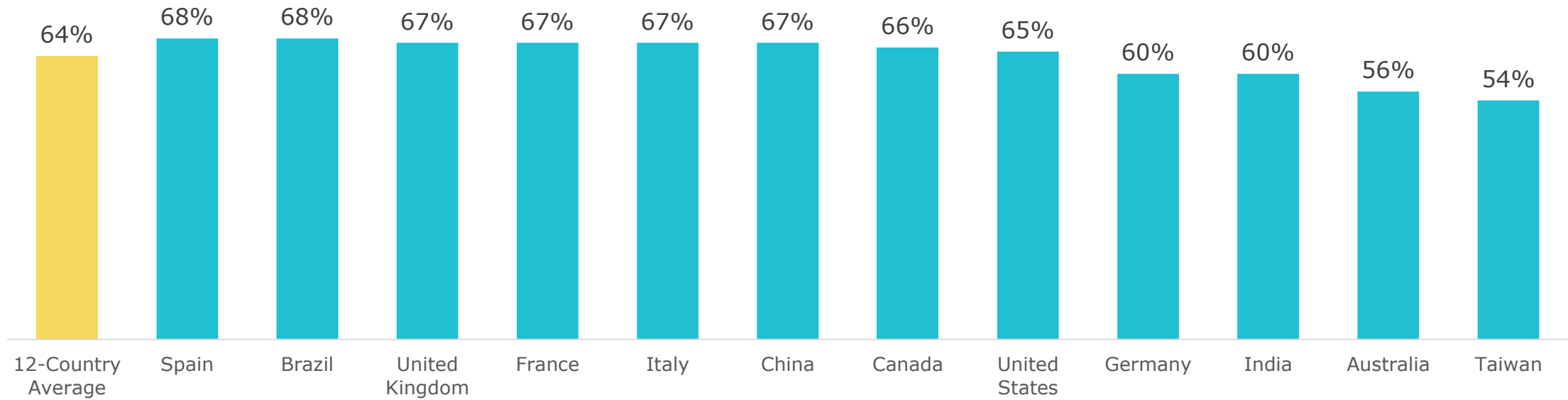
Those who say the person(s) they care for is/are relying on them more than ever before due to the pandemic



Q14. Which, if any, of the following statements is true for you as it relates to how the Coronavirus/COVID-19 pandemic has impacted your ability to provide care? Select all that apply. Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Rising Demands

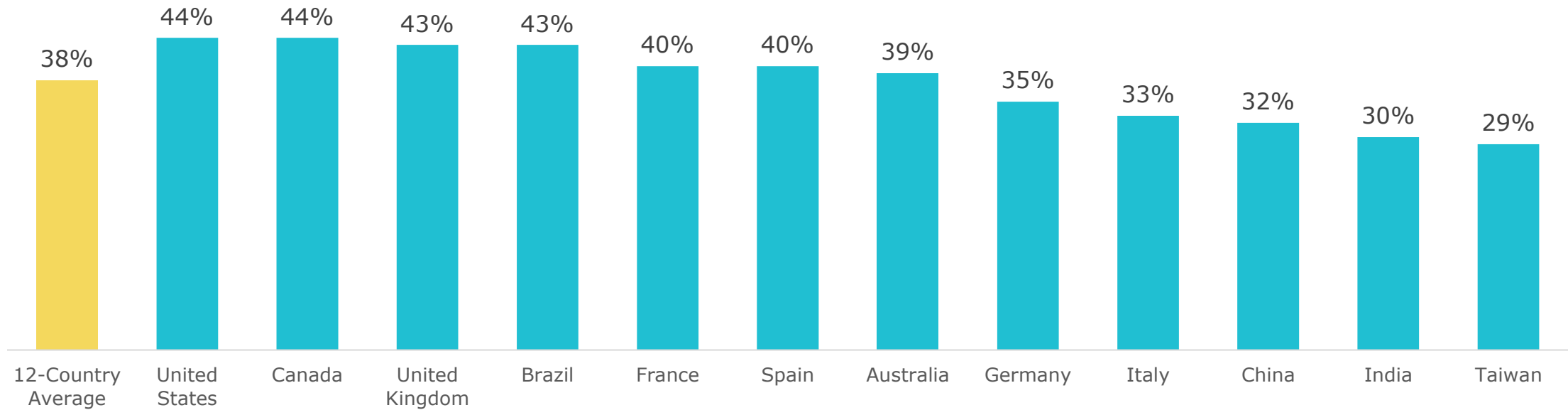
Those who say the pandemic has made caregiving harder



Q9. In general, would you say the Coronavirus/COVID-19 pandemic has made caregiving harder or easier? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

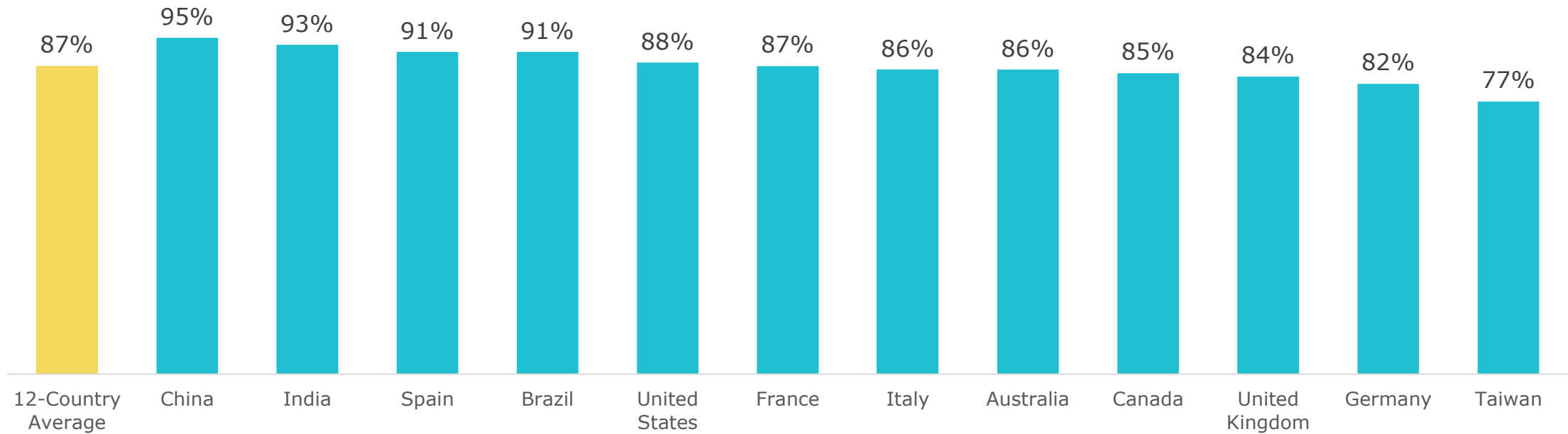
Rising Demands

Those who say the person(s) they care for is/are appreciative of their efforts



Rising Demands

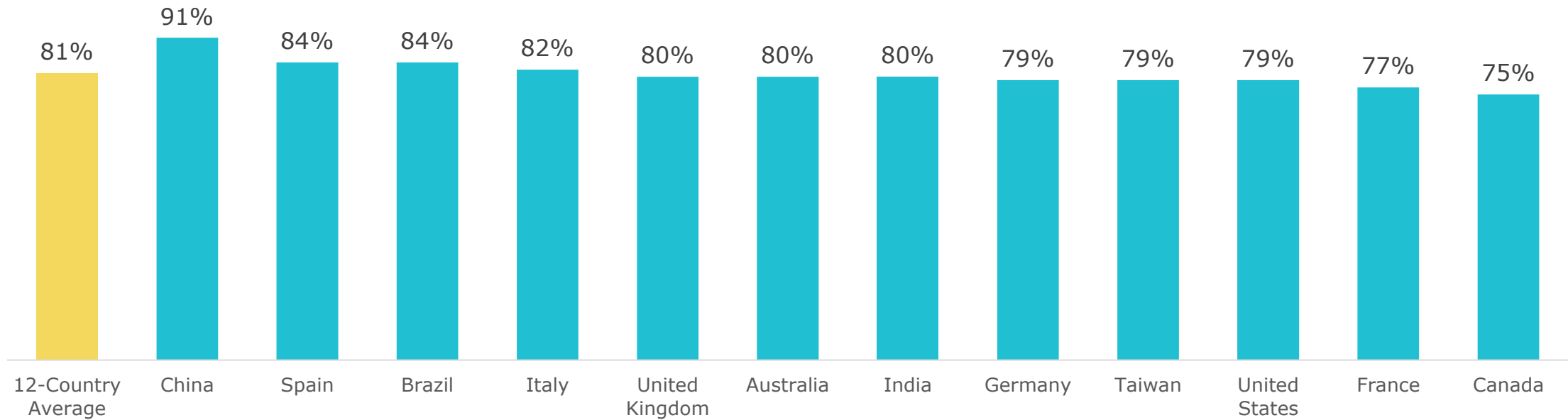
Those who agree that caring for someone during the Coronavirus is hard but it is also very rewarding



The Toll on Carers

To what extent, if at all, do you agree with each of the following statements: [Agree Summary]

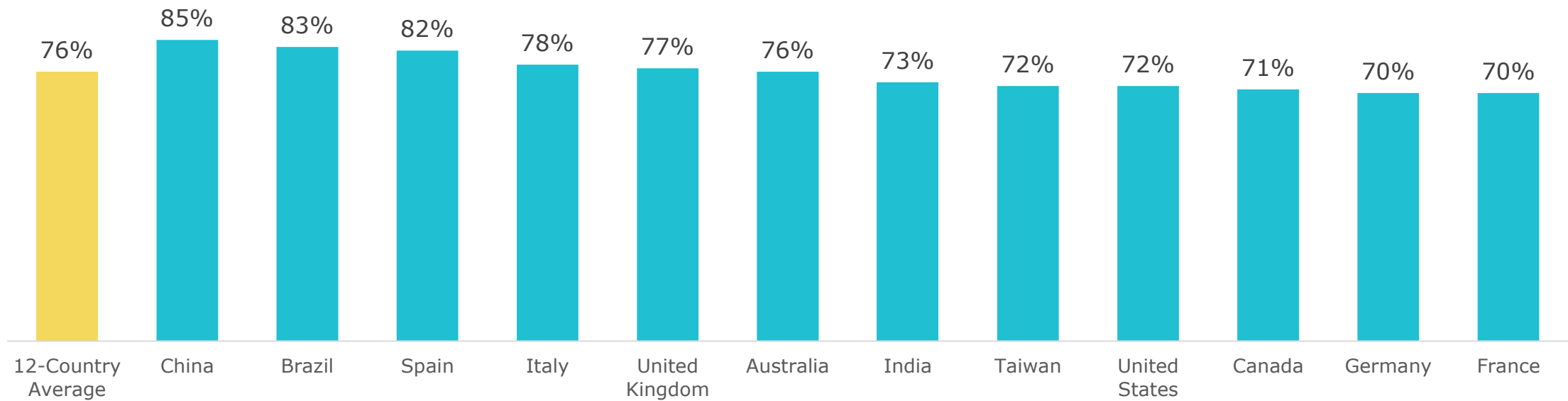
-Since the Coronavirus/COVID-19 began, I've had to sacrifice more of my personal life for the person/people I care for



The Toll on Carers

To what extent, if at all, do you agree with each of the following statements: [Agree Summary]

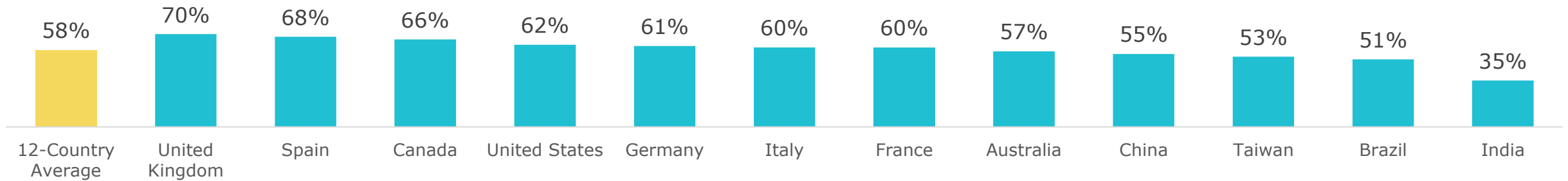
- Caring for someone during the Coronavirus/COVID-19 has caused me to feel more burnt out than ever before.



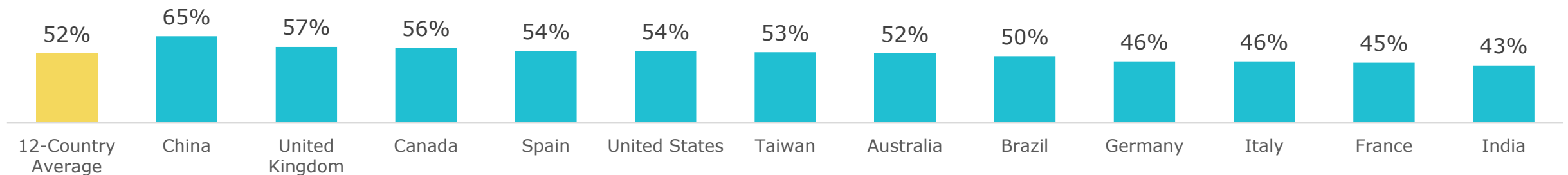
The Toll on Carers

How, if at all, does being a caregiver/carer impact each of the following aspects of your life currently? [Negative Summary]

- My emotional/mental health



- My financial health

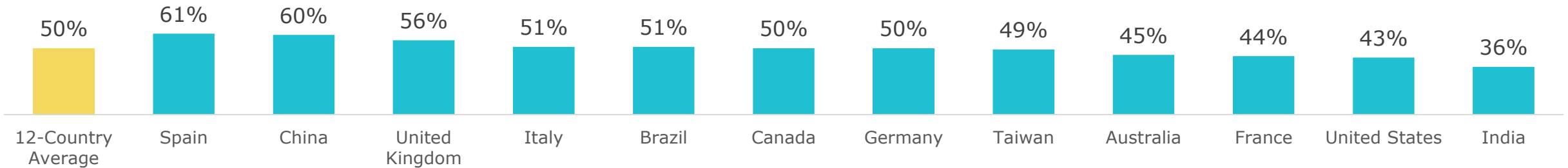


Q5. How, if at all, does being a carer/carer impact each of the following aspect of your life currently? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

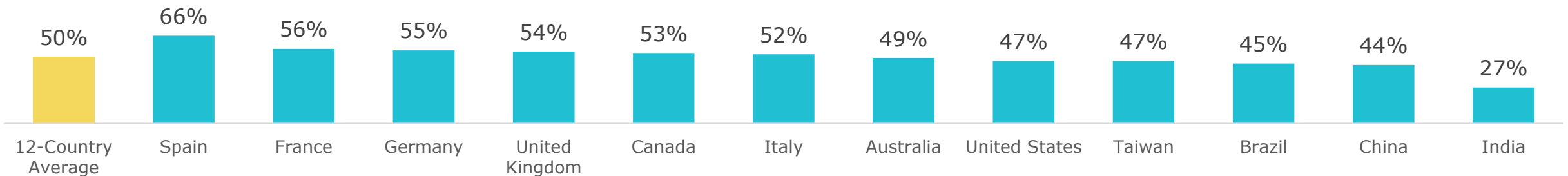
The Toll on Carers

How, if at all, does being a caregiver/carer impact each of the following aspects of your life currently? [Negative Summary]

– My career (e.g., long-term employment goals)



– My physical health

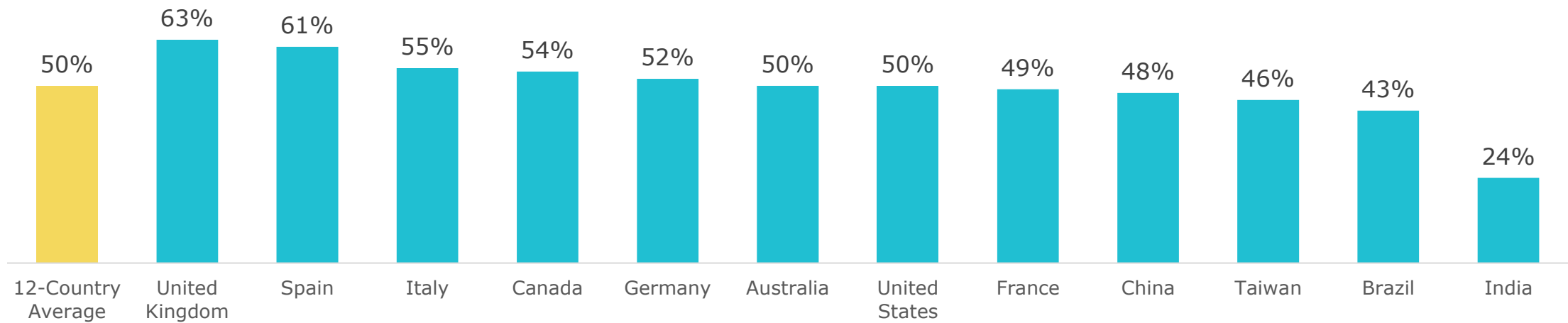


Q5. How, if at all, does being a carer/carer impact each of the following aspect of your life currently? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

The Toll on Carers

How, if at all, does being a caregiver/carer impact each of the following aspects of your life currently? [Negative Summary]

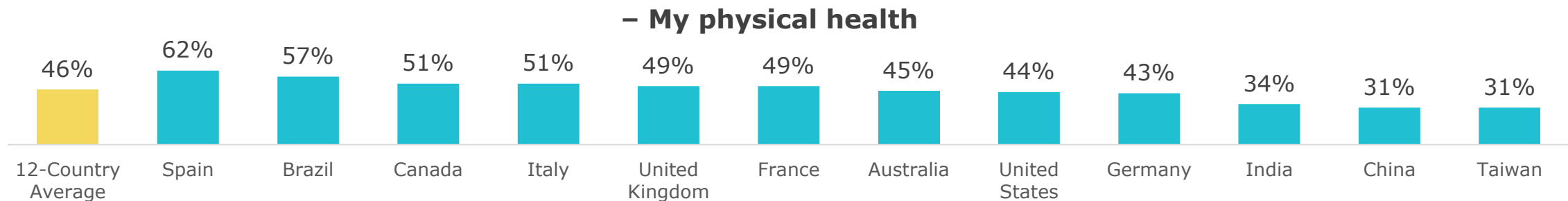
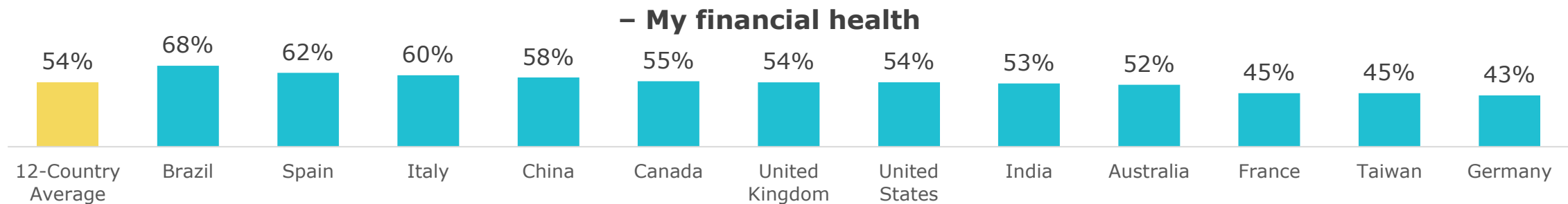
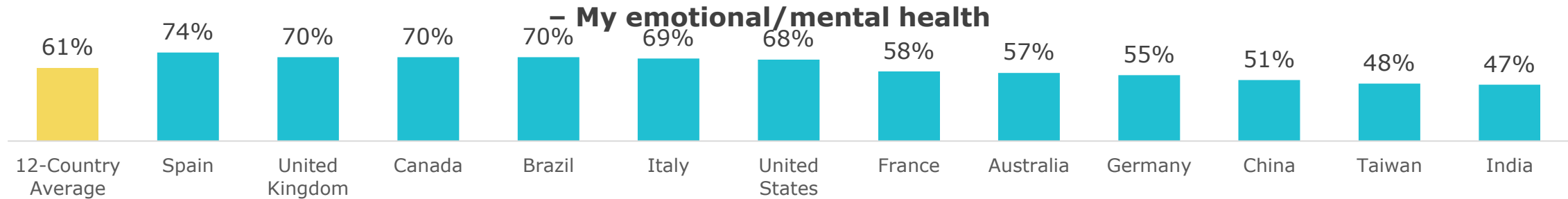
– My relationship with my friends (e.g., my social life)



Q5. How, if at all, does being a carer/carer impact each of the following aspect of your life currently? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

The Toll on Carers

In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? [Worsened Summary]

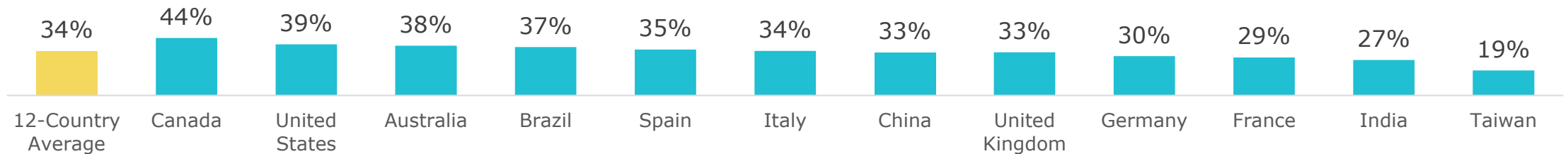


Q12. In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

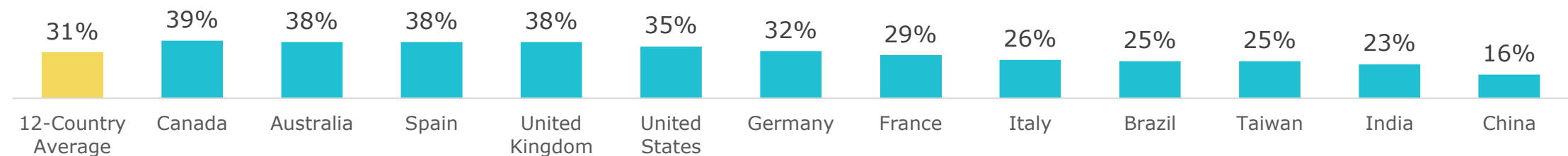
The Toll on Carers

**Earlier in the survey, you mentioned that your emotional/mental health has worsened as a result of the Coronavirus/COVID-19. From the list below, which, if any, of the following statements describe why your emotional/mental health has worsened due the Coronavirus/COVID-19?
[Among carers whose emotional/mental health worsened]**

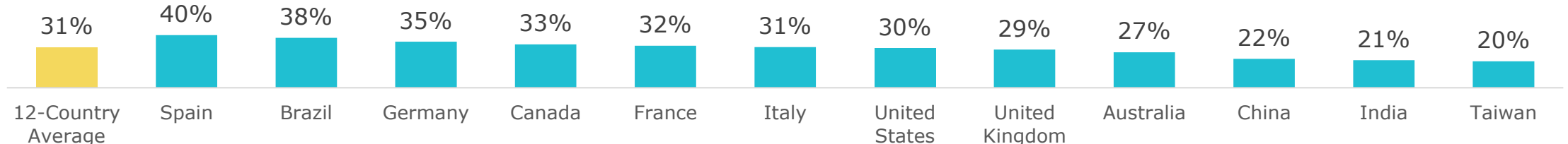
- Physical distancing/sequestering orders have made me feel isolated and alone.



- I have even less time to spend with my family and friends.



- I am more afraid than ever before that the person/people I care for is/are going to die.

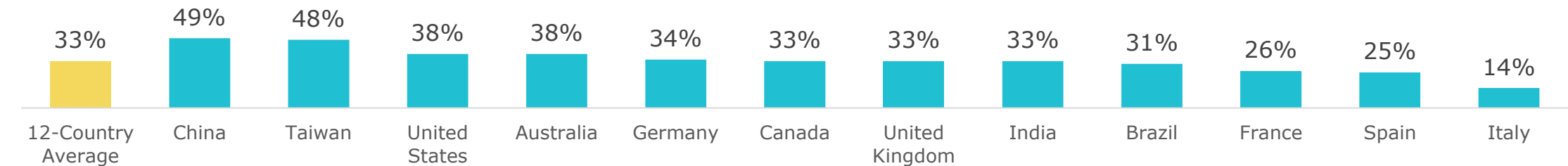


Q17. Earlier in the survey, you mentioned that your emotional/mental health has worsened as a result of the Coronavirus/COVID-19. From the list below, which, if any, of the following statements describe why your emotional/mental health has worsened due the Coronavirus/COVID-19? Please select all that apply. Base: 12-Country Total n=5557; United States n=508; Canada n=527; United Kingdom n=531; France n=443; Germany n=420; Italy n=516; Spain n=554; Australia n=428; Brazil n= 526; Taiwan n=364; India n=353; China n=386

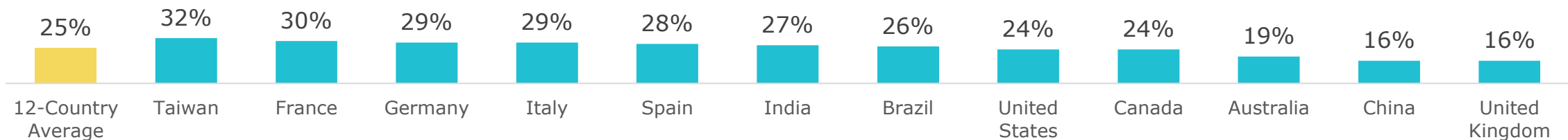
The Toll on Carers

Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due the Coronavirus/COVID-19? [Among carers whose financial health worsened]

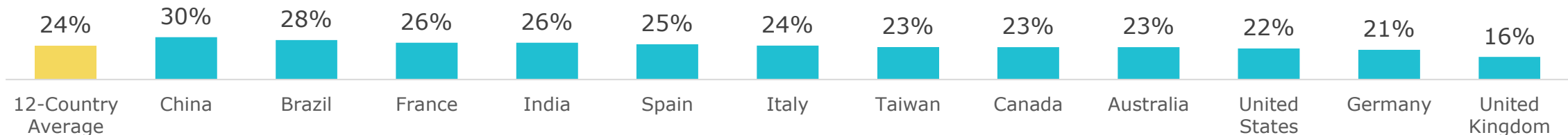
- More of my money is going toward supplies and resources I need to provide care.



- Government/social service/insurance provided financial support is not enough to cover my caregiving expenses.



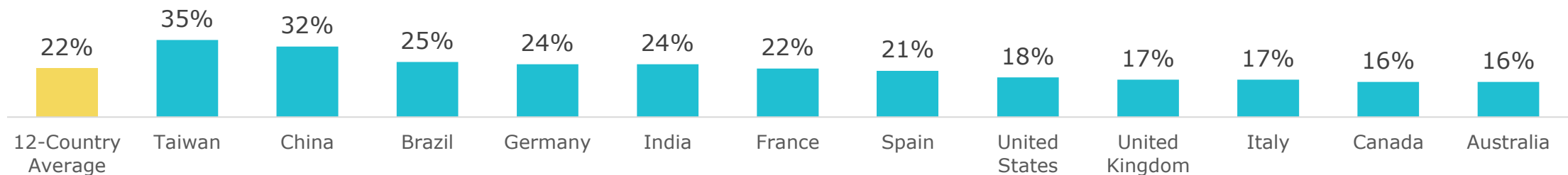
- My professional/paid working hours were reduced/cut back.



The Toll on Carers

Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due the Coronavirus/COVID-19? [Among carers whose financial health worsened]

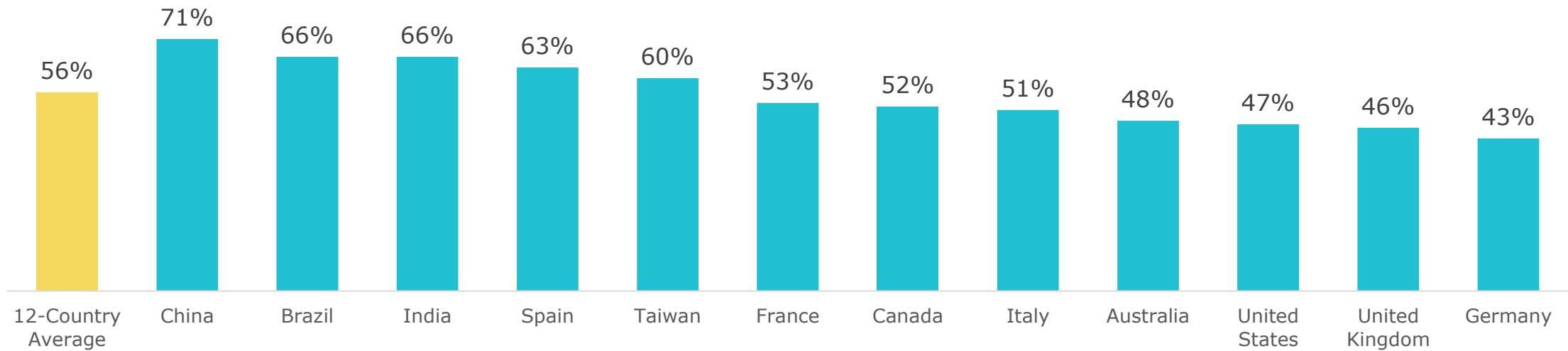
- I've had to reduce my professional/paid working hours because of my caregiving duties.



The Toll on Carers

How do you think your annual household income will be affected by the Coronavirus/COVID-19 pandemic?

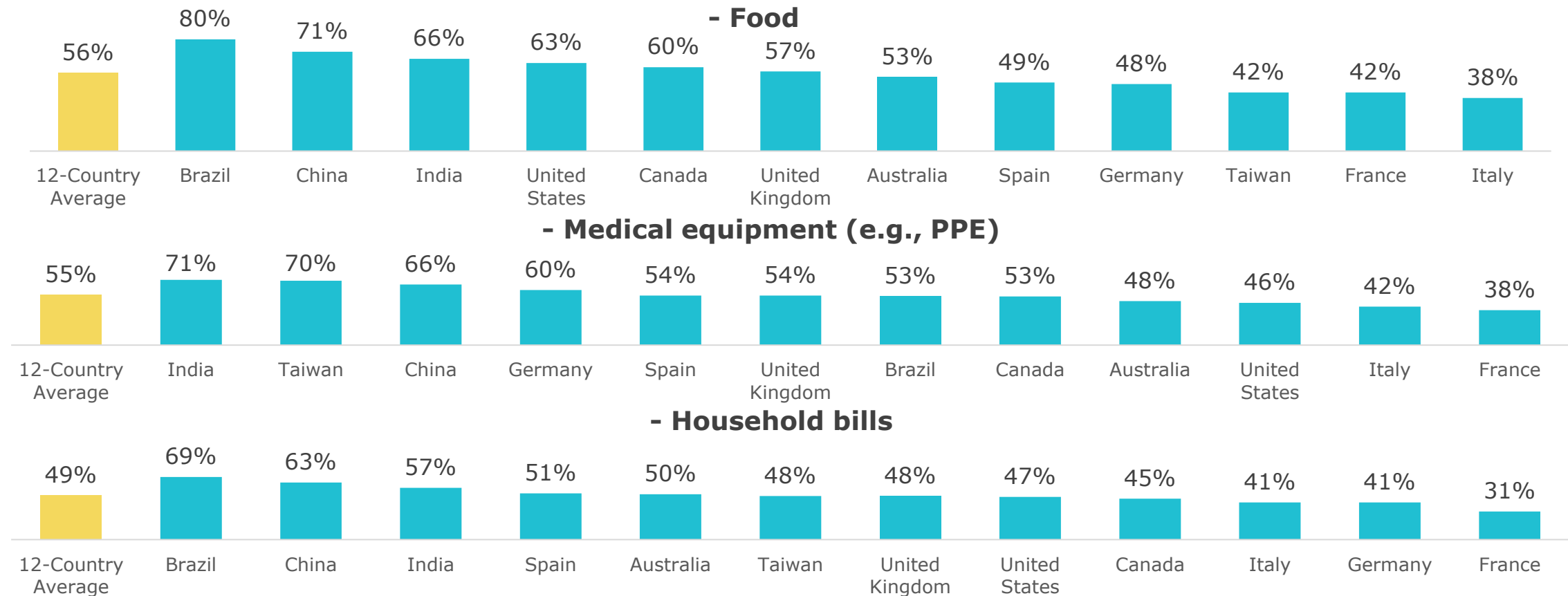
[Decrease Summary]



D3. How do you think your annual household income will be affected by the Coronavirus/COVID-19 pandemic?? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

The Toll on Carers

Since the Coronavirus/COVID-19 pandemic began, are you spending more, less or the same amount of money for each of the following?
[More Summary]



Q21. Since the Coronavirus/COVID-19 pandemic began, are you spending more, less or the same amount of money for each of the following? Choose the phrase that best completes the sentence below..

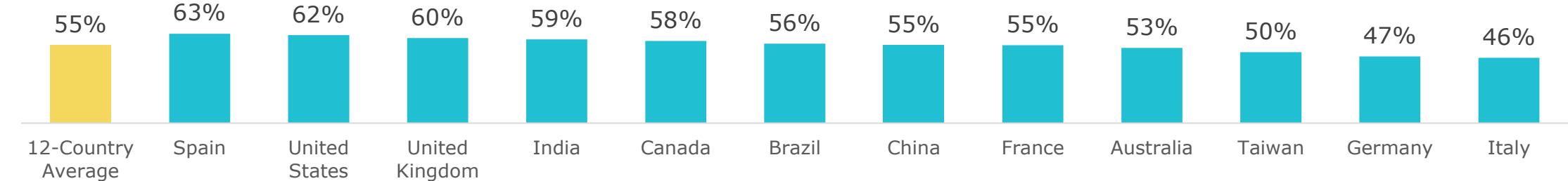
Base: 12-Country Total n=4901; United States n=409; Canada n=418; United Kingdom n=407; France n=345; Germany n=326; Italy n=449; Spain n=469; Australia n=392; Brazil n= 510; Taiwan n=338; India n=399; China n=439

Embracing Carers™ is supported by EMD Serono

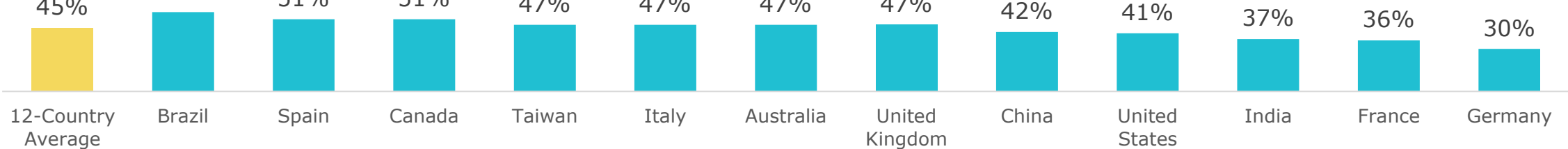
The Toll on Carers

Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due the Coronavirus/COVID-19? [Among carers whose physical health worsened]

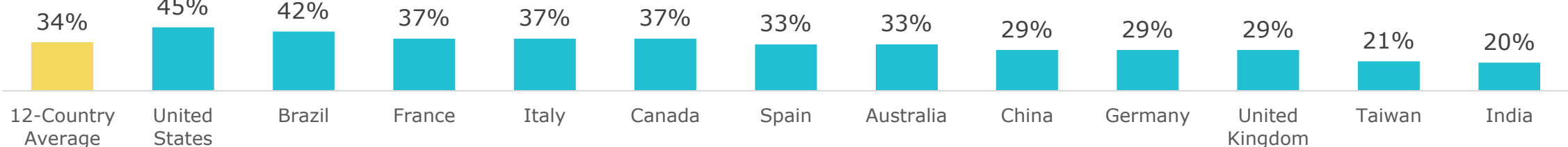
- I am lacking sleep.



- I am exercising less.



- I have postponed my own medical appointments.

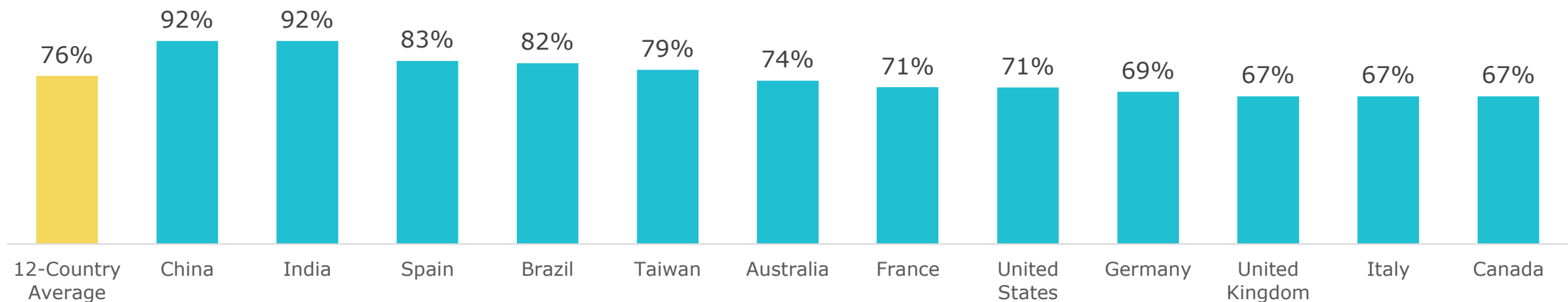


Q19. Now, please select from the below list, which, if any, of the following statements describe why your physical health has worsened due the Coronavirus/COVID-19? Select all that apply. Base: 12-Country Total n=4128; United States n=327; Canada n=382; United Kingdom n=372; France n=375; Germany n=326; Italy n=383; Spain n=467; Australia n=338; Brazil n= 431; Taiwan n=260; India n=233; China n=234

The Toll on Carers

To what extent, if at all, do you agree with each of the following statements: [Agree Summary]

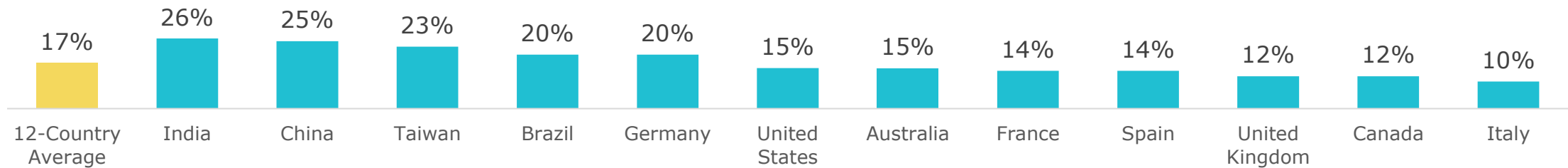
- Connecting with other caregivers/carers who are going through similar situations always makes me feel better.



The Toll on Carers

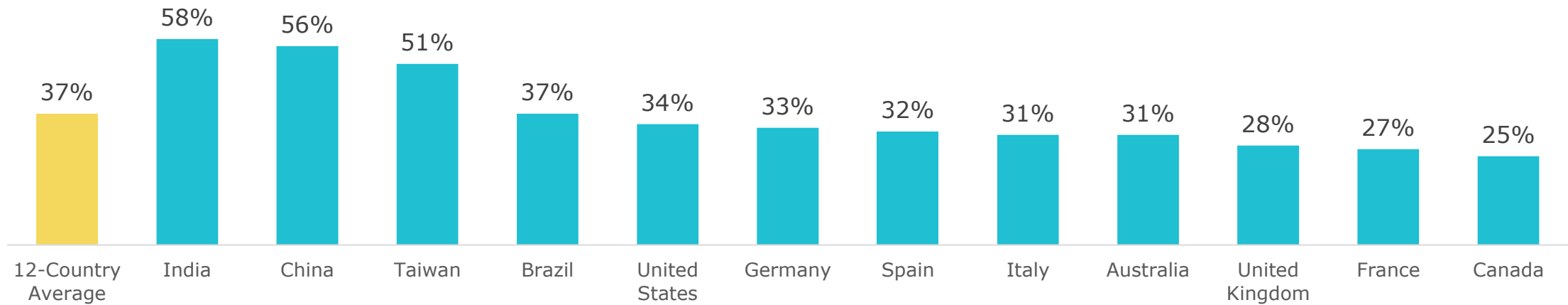
Which, if any, of the following activities have you done since the Coronavirus/COVID-19 pandemic began to help improve your emotional/mental health?

- Talking to other caregivers (online, in-person, or over the phone)



Path to Solutions

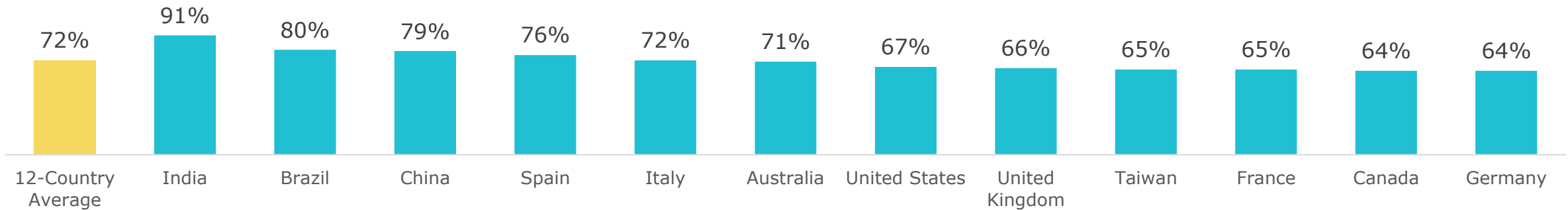
**Since the Coronavirus/COVID-19 pandemic began, are you spending more, less or the same amount of money for technology needed to be a caregiver?
[More Summary]**



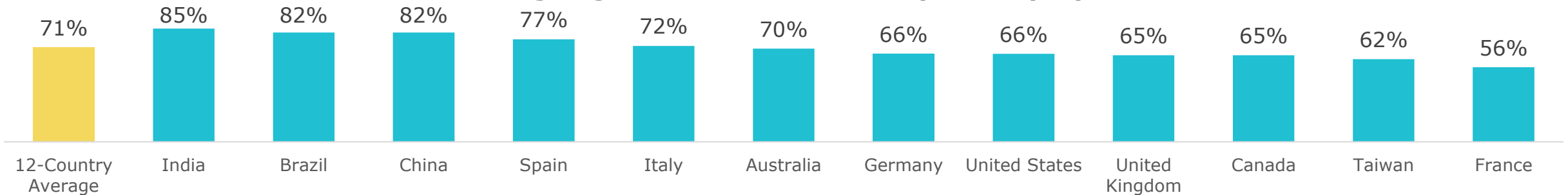
Path to Solutions

**How concerned are you, if at all, about each of the following as it relates to caregiving?
[Concerned Summary]**

– I will have to work full time remotely while also caregiving for the foreseeable future



– I am not going to be able to afford to provide proper care

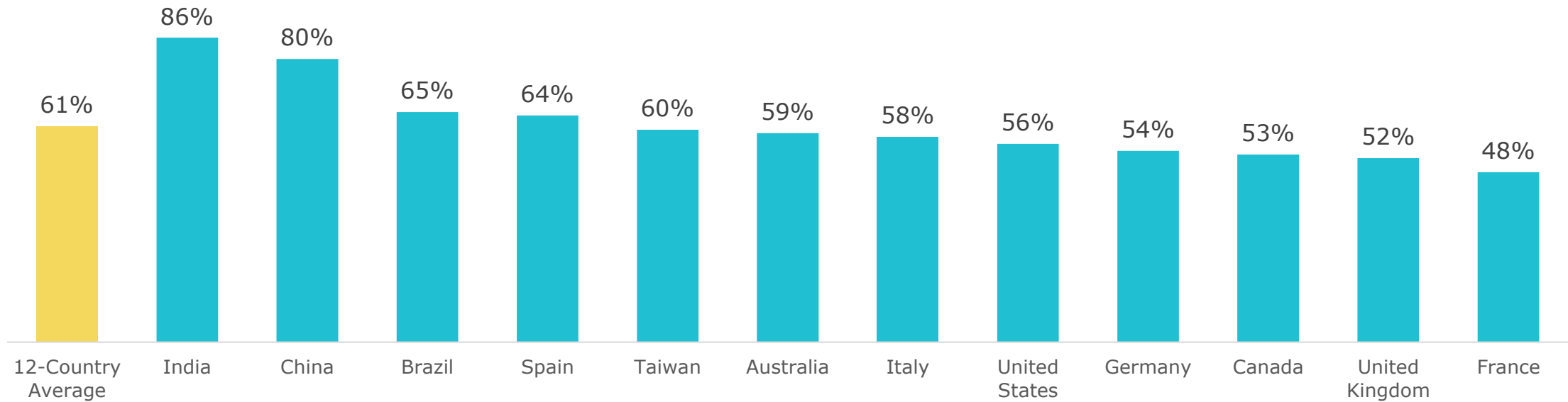


Q26. How concerned are you, if at all, about each of the following as it relates to caregiving? Base: 12-Country Total n=9044; United States n=750; Canada n=755; United Kingdom n=755; France n=759; Germany n=757; Italy n=752; Spain n=751; Australia n=753; Brazil n= 755; Taiwan n=753; India n=750; China n=754

Path to Solutions

**How concerned are you, if at all, about each of the following as it relates to caregiving?
[Concerned Summary]**

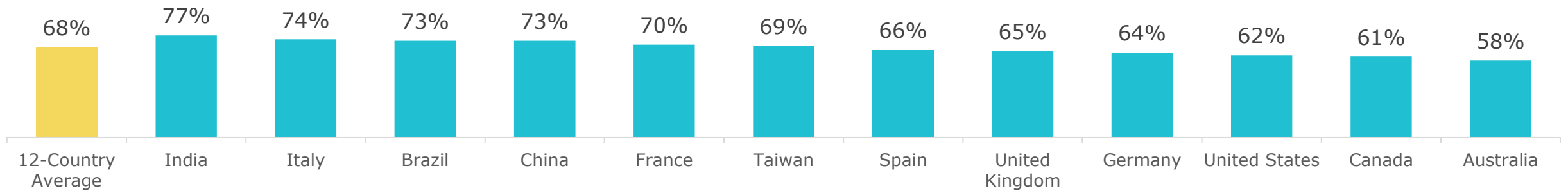
– I will need to use more technology and digital tools to manage care properly



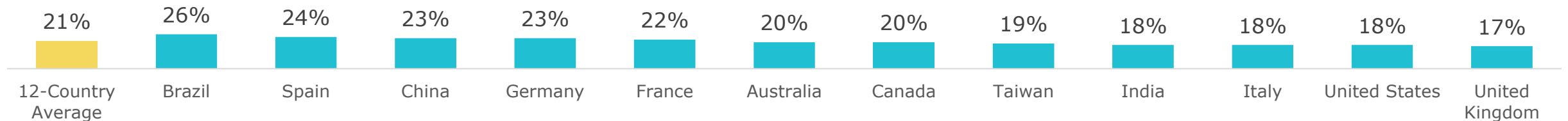
Path to Solutions

Which, if any, of the following are the biggest challenges you've faced as a caregiver/carer during the Coronavirus/COVID-19 pandemic?

– Access



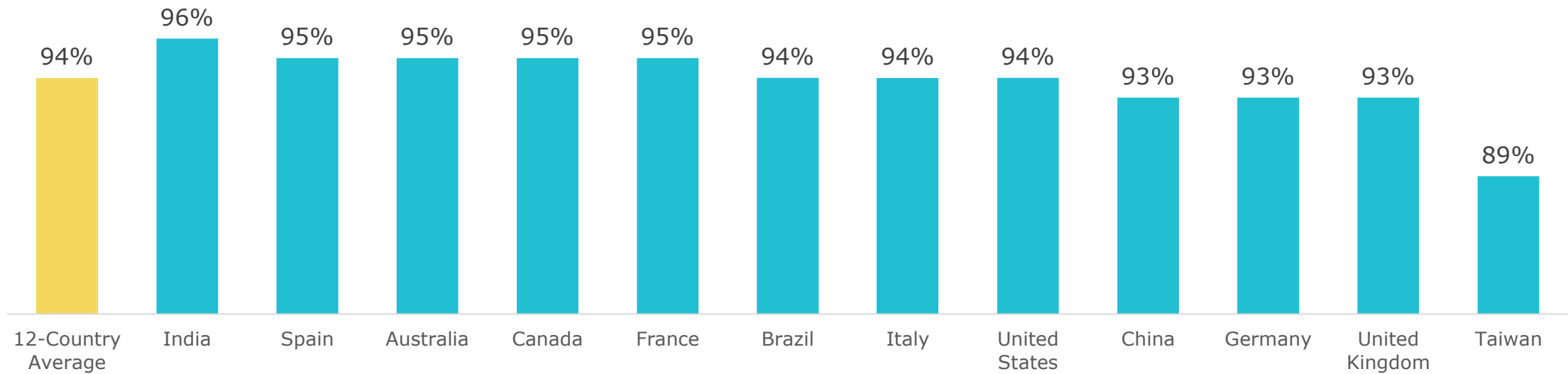
– Difficulty juggling my paid job/career and being a caregiver/carer



Q13. Which, if any, of the following are the biggest challenges you've faced as a caregiver/carer during the Coronavirus/COVID-19 pandemic? Base: 12-Country Total n=9044; Employed Total n=6,280; United States n=750; United States Employed n=414; Canada n=755; Canada Employed n=479; United Kingdom n=755; United Kingdom Employed n=448; France n=759; France Employed n=578; Germany n=757; Germany Employed n=573; Italy n=752; Italy Employed n=499; Spain n=751; Spain Employed n=562; Australia n=753; Australia Employed n=512; Brazil n=755; Brazil Employed n=596; Taiwan n=753; Taiwan Employed n=618; India n=750; India Employed n=488; China n=754; China Employed n=513

Path to Solutions

How much do you agree, if at all, that the important role caregivers/carers have is not widely recognized by society [Agree Summary]



Path to Solutions

In your opinion, are caregiver/carers currently receiving too much, the right amount, or not enough support from each of the following entities? [Not Receiving Enough Support Summary]

| | 12-Country Average | Italy | Brazil | United Kingdom | Spain | United States | France | Germany | Canada | Taiwan | Australia | India | China |
|------------------------------------|--------------------|-------|--------|----------------|-------|---------------|--------|---------|--------|--------|-----------|-------|-------|
| Federal/National Government | 57% | 65% | 63% | 63% | 63% | 61% | 59% | 59% | 58% | 57% | 52% | 45% | 45% |
| Local & state/province government | 56% | 63% | 63% | 62% | 64% | 58% | 57% | 57% | 58% | 55% | 48% | 44% | 44% |
| Private companies | 52% | 57% | 58% | 45% | 59% | 50% | 53% | 51% | 47% | 60% | 39% | 45% | 57% |
| Insurance organizations | 51% | 54% | 54% | 44% | 61% | 54% | 55% | 55% | 52% | 53% | 43% | 44% | 46% |
| Social services/care professionals | 51% | 55% | 52% | 54% | 64% | 52% | 56% | 49% | 53% | 45% | 42% | 41% | 45% |
| Local communities | 50% | 56% | 51% | 45% | 64% | 53% | 52% | 57% | 49% | 53% | 41% | 41% | 37% |