



# COVID-19 COMMUNITY SURVEY REPORT

*95% of Rare Disease Patients Affected*

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The National Organization for Rare Disorders (NORD®) is the leading independent advocacy organization representing over 25 million Americans affected by a rare disease. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90% are still without an FDA-approved treatment or therapy.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 37 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is also home to over 300 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease community.

|  |    |
|--|----|
| Our Mission .....                          | 2  |
| Introduction.....                          | 2  |
| Snapshot of Community Response .....       | 2  |
| Key Findings.....                          | 3  |
| Significant Impact on Access to Care ..... | 3  |
| Financial Impact and Instability .....     | 4  |
| Sources of Worry .....                     | 5  |
| Your Voice Matters.....                    | 5  |
| Life in a Post-Covid World .....           | 6  |
| Figures .....                              | 8  |
| Resources .....                            | 14 |

## INTRODUCTION

The novel coronavirus, and the disease that it causes, COVID-19, is causing significant challenges for millions of Americans living with rare diseases. People with underlying conditions are at risk of more severe illness<sup>1</sup> from COVID-19, and rare disease patients, their caregivers and family members are seeing their lives disrupted in numerous other ways. The National Organization for Rare Disorders conducted a community survey<sup>2</sup> in early April to help understand and bring these issues to light and to support the development of resources that address concerns raised by respondents.

## SNAPSHOT OF COMMUNITY RESPONSE

A total of 772 participants responded to the survey; 72% have a rare disease (16% of whom also care for someone or have a family member with a rare disease), versus others responding as a caregiver or family member. Seventy-five percent are over the age of 40. Participants represent 49 of 50 states (excl: South Dakota) and Washington, DC. Multiple disease categories are represented by participants and their experiences, including genetic conditions, primary immunodeficiencies, neurological, blood, metabolic, movement, eye, skin and other types of rare disorders.

## KEY FINDINGS

It is clear from the survey results that the community is overwhelmingly concerned and impacted by COVID-19; 98% are worried and of those, 67% are very or extremely worried. In addition, 95% have been impacted to some degree at a cost to their immediate and long-term health and well-being.

Sources of concern and worry were varied, though a number of people raised concerns about safely accessing health care if or when needed, feeling unsure about the timing of seeking care (not seeking care too early or waiting too long, for example), medications being out of stock or backordered, and worry about risk of exposure while immunocompromised.

### Respondents told NORD:

- “I worry about being able to tell the difference between COVID symptoms and my norm.”
- “Does my rare disease put me at greater risk for complications due to COVID-19?”
- “How do I know when I should go to a hospital? I’m afraid to go so I’m afraid I’ll wait too long.”
- “Am I putting myself more at risk by leaving the house and entering a hospital setting?”
- “Didn’t go to [the] ER when [I] normally would.”

### Caregivers and family members, who often provide 24/7 care, shared another set of concerns:

- “Very concerned about who would care for my child if I get sick.”
- “Concerned about who will care for our son if we both become ill. Concerned about my son having the virus and requiring hospital care.”
- “Navigating health insurance and medical advocacy... when [we] have a non-verbal and non-ambulatory individual but there are restrictions about who can accompany them in the hospital.”

**74%** Have had a medical appointment **CANCELED** due to COVID-19

## SIGNIFICANT IMPACT ON ACCESS TO CARE

Findings show that 39% of participants have faced challenges accessing medical care or treatment, and 74% have had a medical appointment canceled. This is significant, as many people with rare diseases spend months and even years trying to pinpoint a diagnosis or find therapeutic relief, via long-awaited visits with specialists, advance scheduling for testing procedures, travel to meet with medical experts and participation in research and clinical trials.

### People shared the following with NORD:

- “My infusions are given in a hospital and have been suspended.”
- “Pain procedure considered elective.”
- “With doctor’s input we have decided to stop maintenance chemo.”
- “My infusion was delayed by the delay in receiving COVID test results.”
- “Very concerned about clinical trials in our rare disease...Newest trial just rolled out and now no one can enroll.”
- “It is EXTREMELY difficult for him to be isolated and all community activities stopped. This not only affects the obvious, but I am also concerned about social regression.”

Technology is being leveraged to provide services while social distancing measures postpone “elective” procedures and appointments, yet only 65% of respondents who saw appointments canceled were offered an alternative

**59%** Have been offered a telephone or video call as an alternative to an in-office appointment



<sup>1</sup> “People Who Are at Higher Risk for Severe Illness.” Centers for Disease Control and Prevention, April 17, 2020. [www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html](http://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html).

<sup>2</sup> The NORD COVID-19 Community Survey was promoted to the rare disease community through NORD’s website and social media channels, was open to the public for one week, and closed on April 8, 2020. Responses were collected anonymously. Hypothesis testing to compare the associations between the variables was conducted using IBM® SPSS Statistics software.

via telephone or video. Overall, whether a participant had a scheduled in-person appointment canceled or not, 59% of survey respondents were offered a telemedicine appointment. Future surveying will examine how telemedicine is evolving in light of advocacy efforts and as the pandemic continues to unfold.

**69%**  
Concerned about medication and medical supply shortages



In addition, 69% of respondents are concerned about medication and medical supply shortages; 18% have been unable to access medication for their rare diseases (primarily due to shortages or insurance prohibiting more than the standard 30-day or 90-day supply; *Figure 1.1*); and 17% have had trouble procuring medical supplies and devices (predominantly with issues surrounding personal protective equipment, or PPE, and infusion services; *Figure 1.2*).

**Survey participants reported the following issues:**

- “My prescription of hydroxychloroquine was back ordered (I also have primary Sjögren’s syndrome).”
- “Those with Addison’s now face a shortage of their hydrocortisone.”
- “Online pharmacy doesn’t have med for home delivery.”
- “Mail order pharmacy had delay in reaching doctor.”
- “I am also concerned with the lack of acetaminophen oral liquid to purchase for my toddler. She had stage 1 kidney disease so she can’t have ibuprofen.”

- “Since blood donations are down, I am concerned that I may have trouble getting my immunoglobulin therapy.”
- “People with rare diseases and invisible illness need those masks always.”

Although people expressed difficulty accessing personal protective equipment (PPE), no association was found between PPE access challenges and the severity of impact of COVID-19. This may indicate that people with rare diseases and their families are used to practicing protective health measures. Limited access to PPE is causing challenges and frustration perhaps because it is disrupting regular health practices, rather than because of a specific link to the impact of COVID-19. Future surveying will further examine PPE issues as well as the prevalence of COVID-19 in the rare community.

**FINANCIAL IMPACT AND INSTABILITY**

As unemployment rises due to the impact of COVID-19<sup>3</sup>, 29% of respondents have lost jobs, 11% of whom also lost access to health insurance with the change in job status. The majority of these respondents (74%) identified as the patient’s caregiver or family member. In addition, 40% of households are experiencing a loss of income. For those who have been unable to access their medication, 10% say it is because they can no longer afford it due to lost income (*Figure 1.1*).



Financial instability has the potential for devastating consequences. As a recent NORD study (“Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30 Year Follow-Up”) found, 76% of people experience great (30%) or some (46%) financial burden as a result of their rare disease, and this is without the added impact from COVID-19.

Comparative analyses show significant associations between severity of impact and canceled medical appointments (*Figure 1.3*); challenges accessing medical treatment (*Figure 1.4*); concern over future medication and medical supply shortages (*Figure 1.5*); and loss of income (*Figure 1.6*).

**SOURCES OF WORRY**

Faced with such significant changes to life as we have known it, it is no wonder that 98% of respondents are feeling worried as a result of the COVID-19 outbreak. It seems worth noting that the challenges related to medical care show the strongest association with level of worry, specifically: the ability to access medication (*Figure 1.7*) or medical supplies and devices (*Figure 1.8*), both now and in the future (*Figure 1.9*). The data also shows a significant association between level of worry and a household loss of income (*Figure 1.10*).

While individual experiences with rare diseases may vary, the community appears united in its shared concern over this issue. Even among the small percentage (5%) of respondents not impacted by COVID-19, more than half (54%) are worried about future medication and medical supply shortages (*Figure 1.5*).

**YOUR VOICE MATTERS**

NORD is listening to the patients and families in our community and we will continue to channel your collective voices into action. Here are some of the most common concerns shared by survey respondents:

**Accessing Medical Care:**

Many expressed concern about not being able to access medical care should hospitals become overwhelmed and face medical triage decision making:

- “I worry when they are starting to say they will have to prioritize who gets the ventilators and that some patients in need may be denied. I worry that rare disease patients will be in the group of first patients denied ventilators if needed. Am I right to be concerned?”
- “Will my sister be lower on priority for respirators if she gets sick?”
- “Can we count on hospitals and government to treat us if we become ill?”
- “Without sufficient ventilators I would be last on the list.”

**Workplace Discrimination:**

People are also worried about discrimination and workplace rights:

- “Can a company be required to allow employees to work from home if they live with someone who is immunosuppressed?”
- “My company is requiring us to come in even if we are high-risk. [I need] help with understanding legalities of companies not making provisions for those that are high-risk due to rare disease or [being] immunocompromised.”

<sup>3</sup> Schwartz, Nelson D. “Nowhere to Hide’ as Unemployment Permeates the Economy.” The New York Times. <https://www.nytimes.com/2020/04/16/business/economy/unemployment-numbers-coronavirus.html>, April 16, 2020.

NORD has and will continue to take action on federal and state levels to prevent discriminatory action and protect people with rare diseases.

**Lost Loved Ones:**

As COVID-19 spreads, more and more lives will be forever changed. NORD stands with everyone who is affected and will continue to bring awareness to how this virus is impacting people living with rare diseases.

- “We lost our son to what doctors now think may have been COVID prior to testing availability.”
- “We lost our 11-year-old son within 16 hours of his first symptom.”
- “My father has a triple risk due to age, stage 4 cancer and lung disease and at the end of life with his rare cancer and we have to isolate him to protect him from being exposed. We are sad [and] conflicted about what is worse for him - to isolate him so there is almost no risk of him being infected or for him to spend a large portion of his last time of life physically alone.”
- “My brother, with whom I live, is considered an essential worker and is therefore going into his public workspace every day and coming home every night. Should I self-quarantine in my house away from my brother?”

**LIFE IN A POST-COVID WORLD**

Understandably, people also want answers about the future:

- “Wondering how I will remain healthy once the restrictions are lifted and others go back to their life. Will the virus be hiding out and as threatening to me then as it is now?”
- “When will we be able to schedule and attend appointments with specialists again?”
- “When will it be over? Once gone will it come back again?”

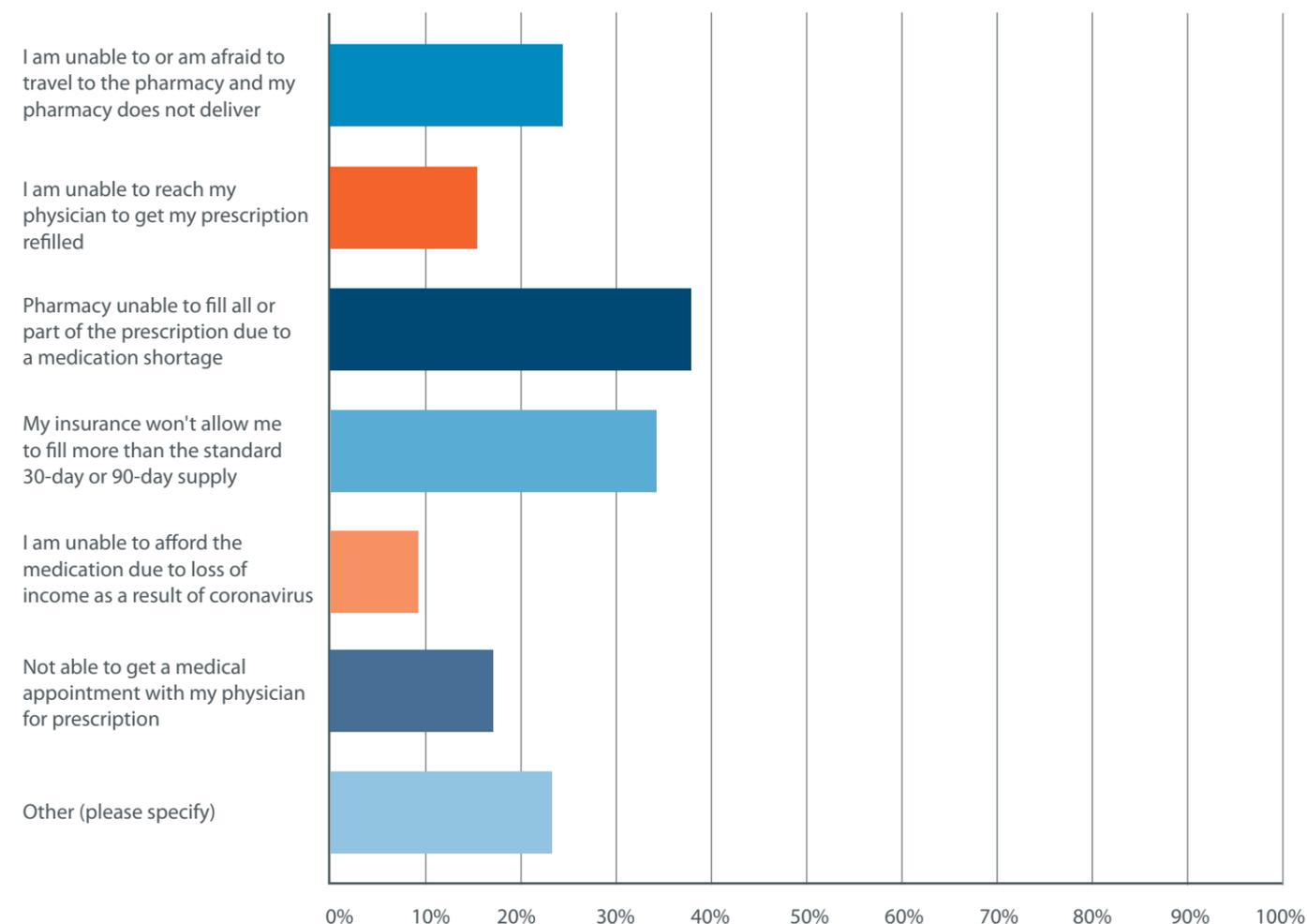
NORD is planning a follow-up survey in order to continue to monitor the experiences and impact that our community is facing.

**FIGURES**

*Below are the responses from the 18% of individuals who reported challenges with getting medication for a rare disease.*

**Figure 1.1**

**What was the challenge with getting the medication? (Select all that apply)**

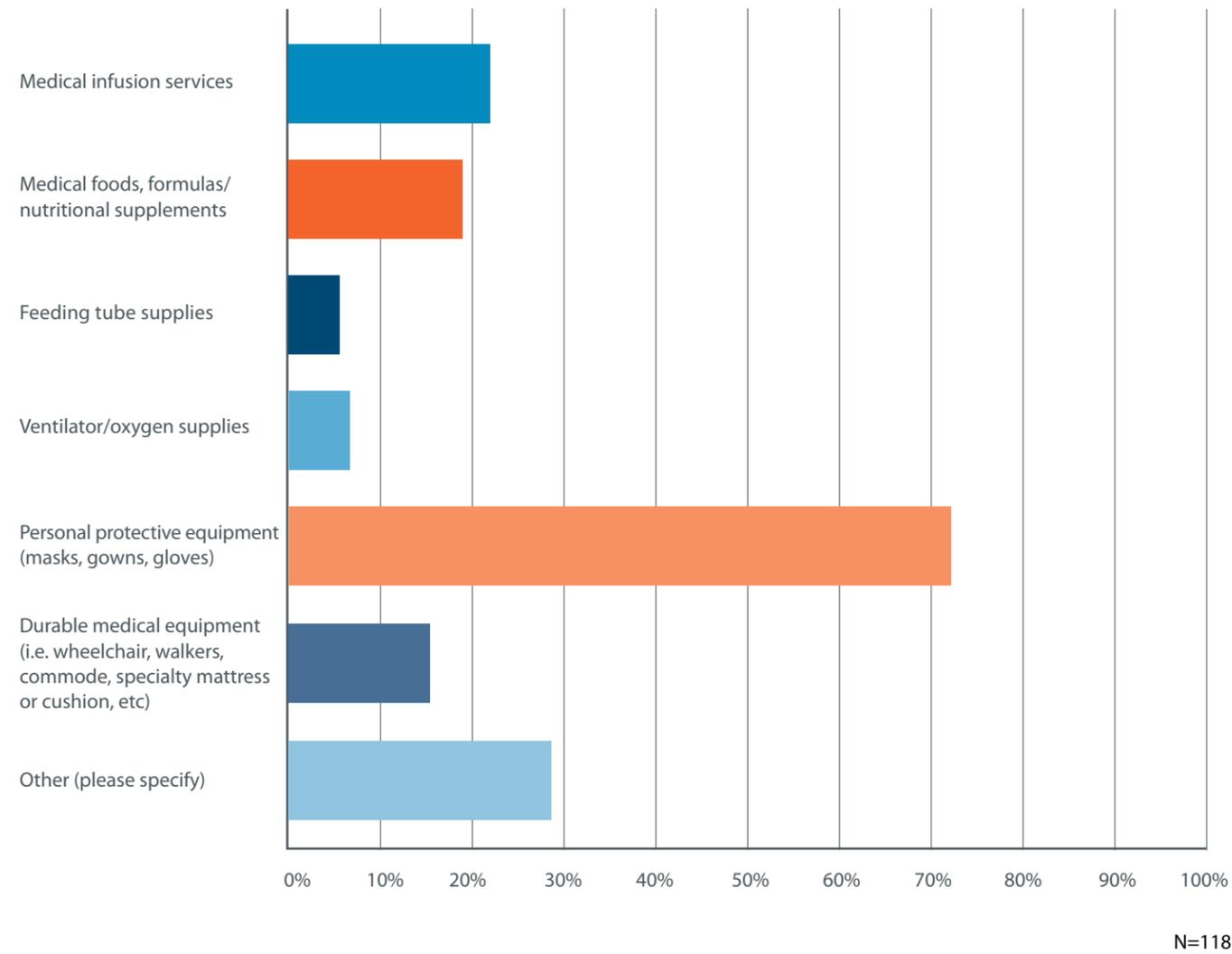


N= 128

Below are the responses from the 17% of individuals who reported challenges with accessing medical supplies or devices for a rare disease.

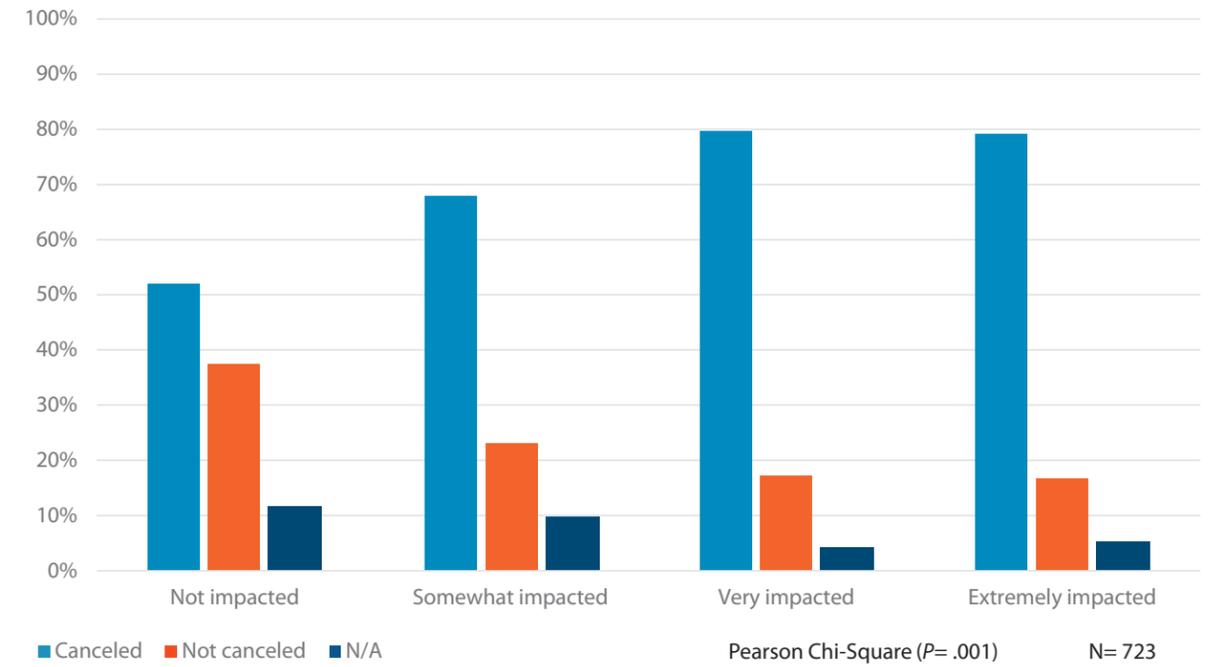
**Figure 1.2**

**What medical supplies and devices have you had challenges getting? (Select all that apply)**



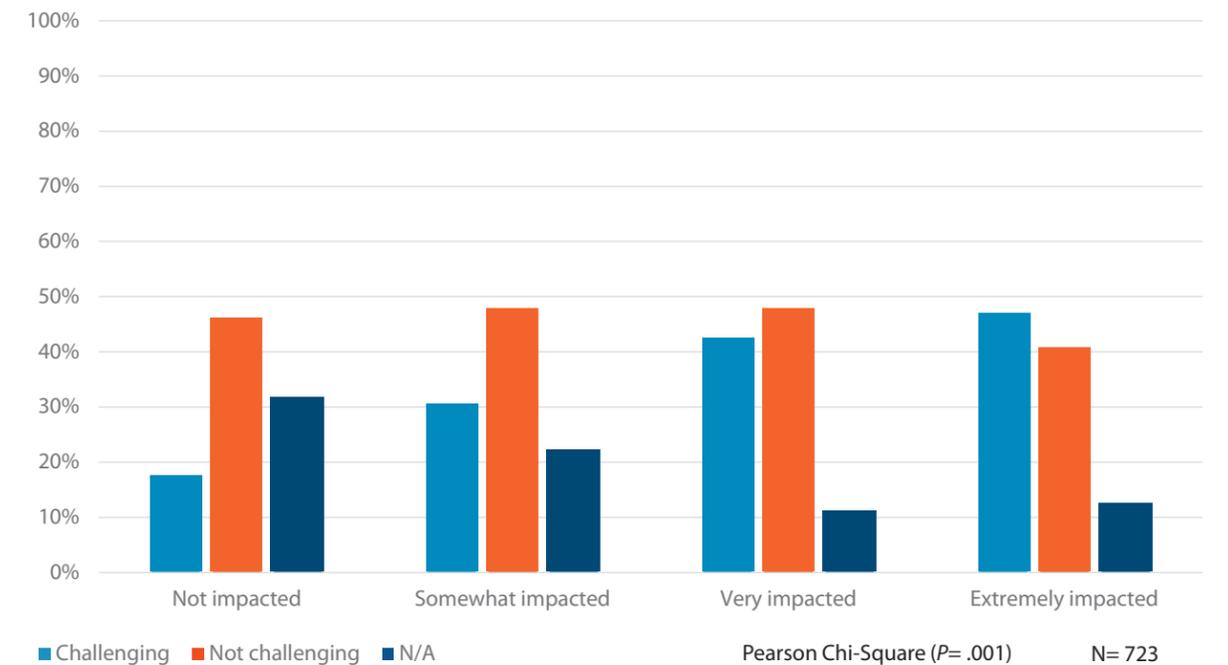
**Figure 1.3**

**The association between being impacted by coronavirus (COVID-19) and having had a medical appointment canceled due to coronavirus (COVID-19)**



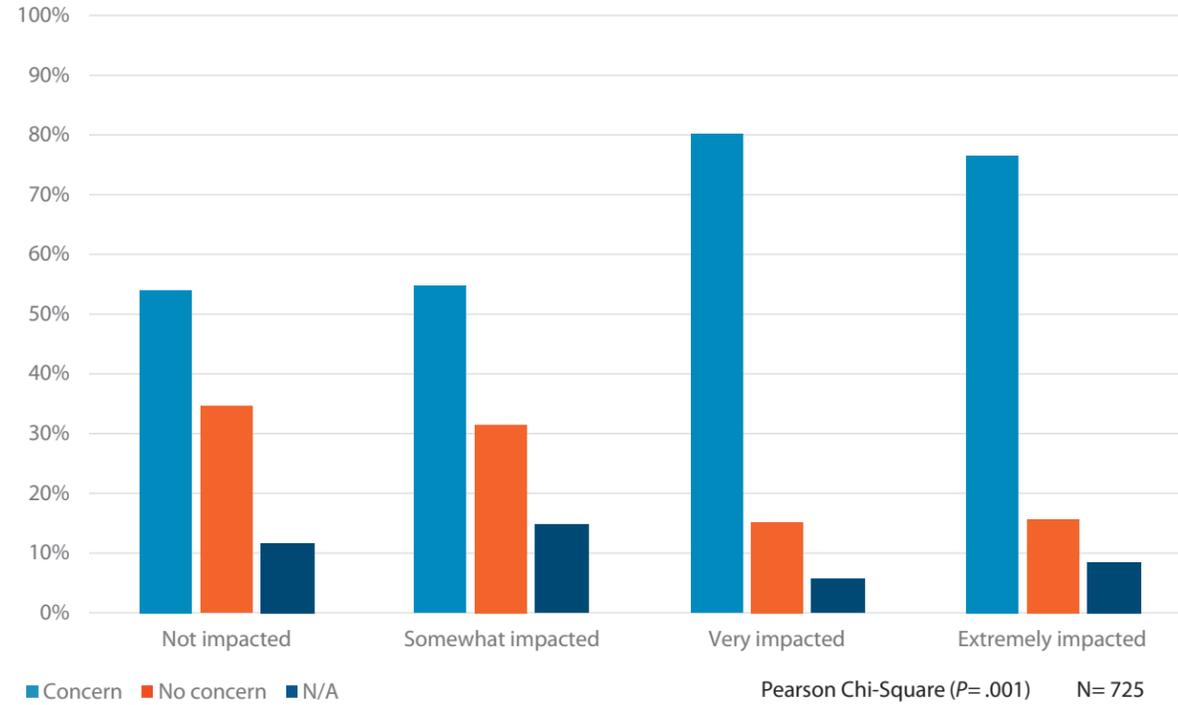
**Figure 1.4**

**The association between being impacted by coronavirus (COVID-19) and having experienced any challenges with accessing medical care or treatment**



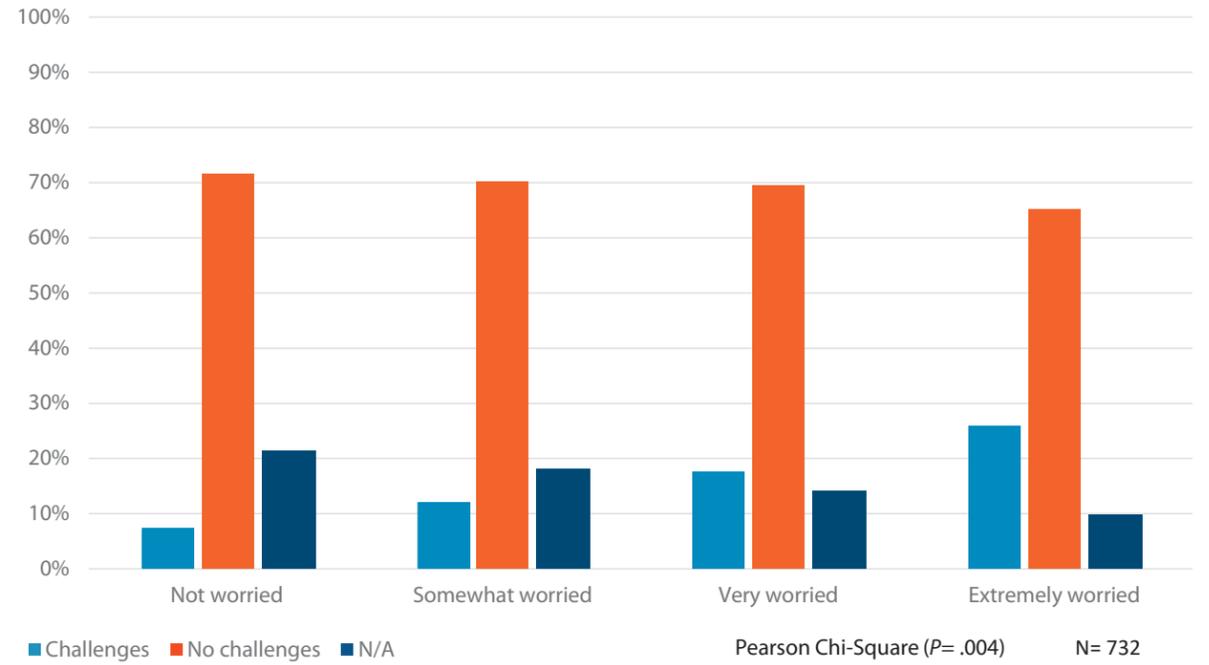
**Figure 1.5**

The association between being impacted by coronavirus (COVID-19) and concern with future medication and medical supply shortages



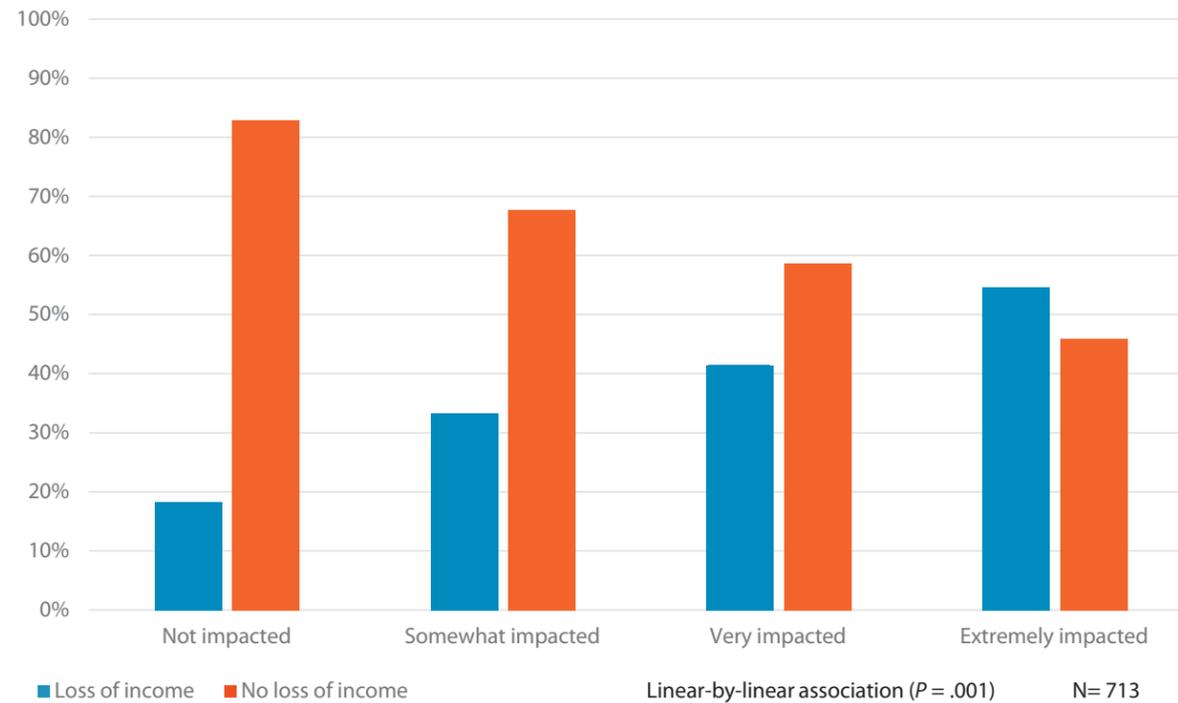
**Figure 1.7**

The association between being worried about coronavirus (COVID-19) and having experienced any challenges getting medication for a rare disease due to coronavirus (COVID-19)



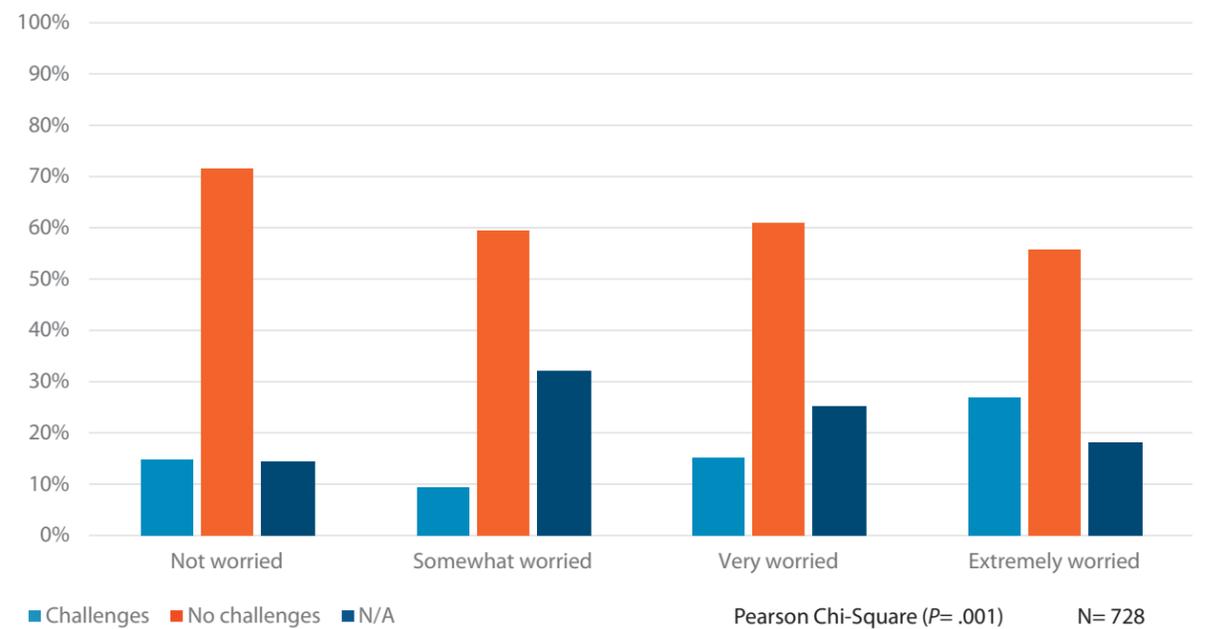
**Figure 1.6**

The association between being impacted by coronavirus (COVID-19) and having a household impacted by a loss of income due to coronavirus (COVID-19)



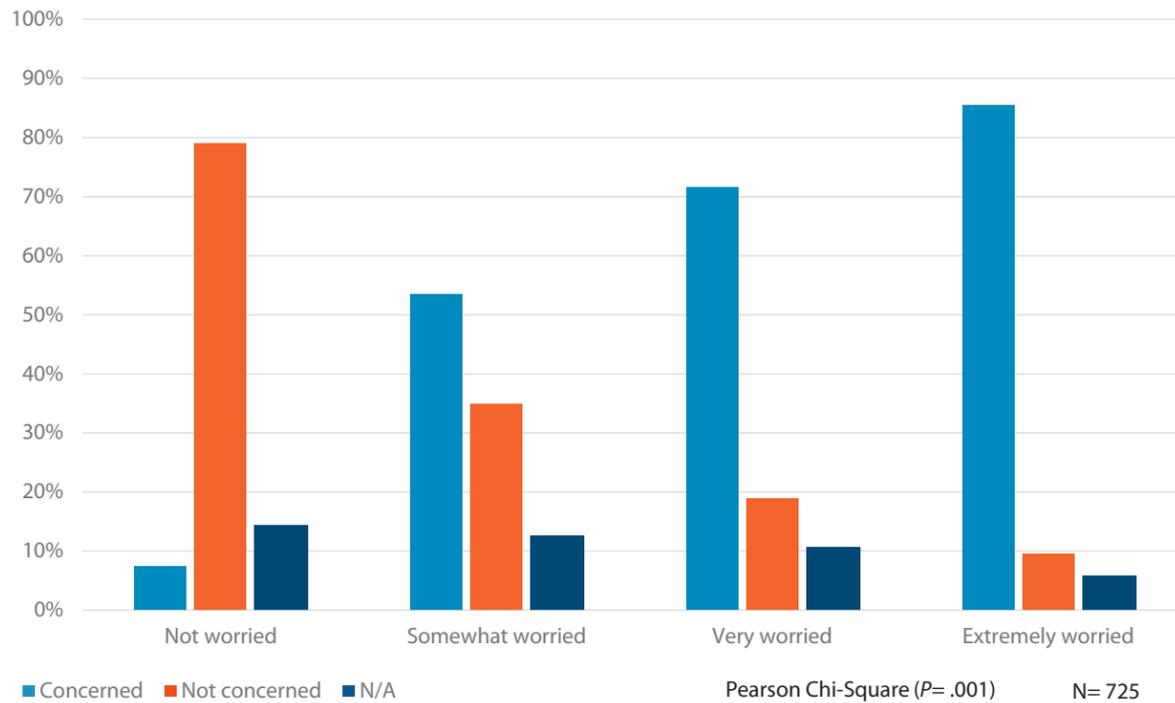
**Figure 1.8**

The association between being worried about coronavirus (COVID-19) and having experienced any challenges getting medical supplies and devices for a rare disease due to coronavirus (COVID-19)



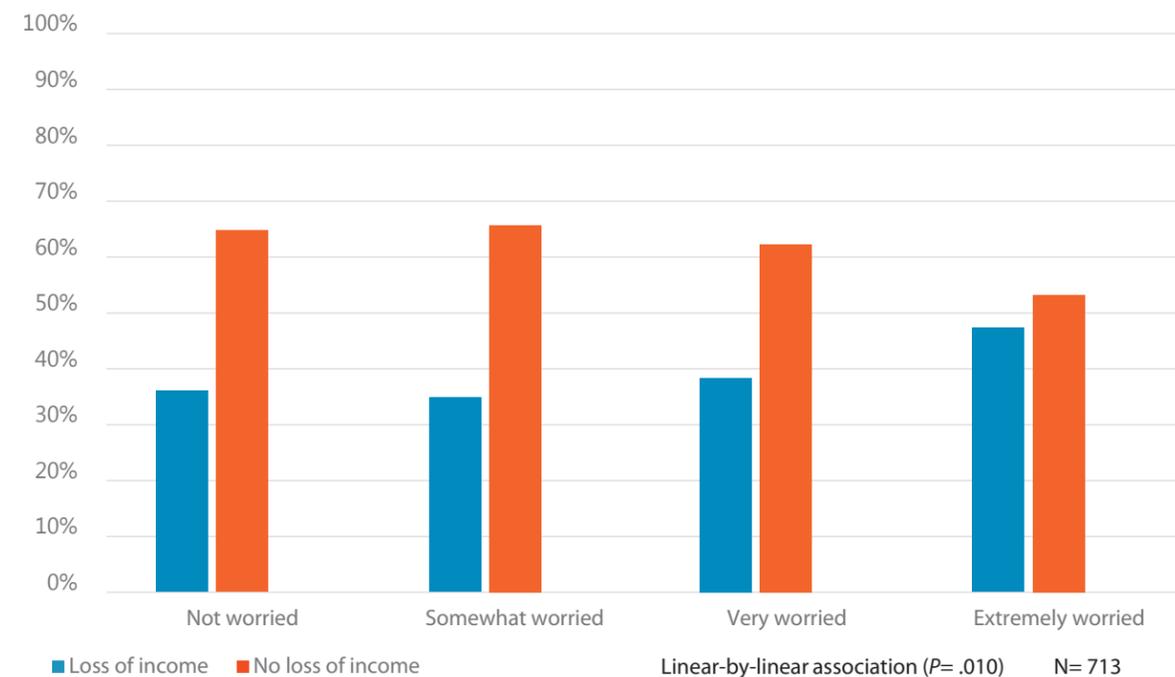
**Figure 1.9**

**The association between being worried about coronavirus (COVID-19) and concern with future medication and medical supply shortages**



**Figure 1.10**

**The association between being worried about coronavirus (COVID-19) and having a household impacted by a loss of income due to coronavirus (COVID-19)**



**RESOURCES**

As part of responding to the unprecedented and evolving COVID-19 situation, NORD has developed the NORD COVID-19 Resource Center ([rarediseases.org/covid-19/](https://rarediseases.org/covid-19/)), offering resources to help the rare disease community, to address concerns raised by survey respondents and to share real-time updates on actions NORD has taken in response to the pandemic. Our team is working to address as many concerns as possible while also continuing NORD's other vital programs and services.

Readers of this report are encouraged to take action by joining NORD in advocacy efforts to call on lawmakers to prioritize public health in COVID-19 response legislation, to share any other concerns with respect to the COVID-19 pandemic via this [form](#), and to visit the NORD COVID-19 Resource Center for future updates.

NORD's lines are always open ([rarediseases.org](https://rarediseases.org); [orphan@rarediseases.org](mailto:orphan@rarediseases.org); 203-744-0100).

**ACKNOWLEDGEMENTS**

Thank you to the patients, families, caregivers and patient advocates for participating in this survey.

**ABOUT RAREINSIGHTS**

RareInsights™ is a NORD initiative to expand public knowledge of rare diseases and translate that knowledge into real-world solutions for patients and families.

Through this initiative, NORD is commissioning and undertaking a broad range of projects to collect and analyze empirical data for next-generation advocacy that is patient-centered and data-driven. Information is shared with the community in a variety of accessible formats, including reports, white papers, infographics, fact sheets, and more.