



COVID-19 Coping Study

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Study Description:

The COVID-19 (coronavirus) 2020 pandemic has dire immediate and long-term consequences for the health and well-being of Americans. Older adults are not only at higher risk for severe morbidity and mortality from COVID-19, but are also particularly vulnerable to physical and emotional harms associated with the pandemic. For example, thousands of residents in nursing homes and assisted living facilities are now not allowed to leave their rooms or receive visits from family members or friends. Care provided to community-dwelling older adults from home health aides and certified nursing assistants is disrupted, and visits from family and friends are discouraged or prohibited due to social distancing recommendations or shelter in place orders. Widespread ageism in the daily news and popular culture depicts “the elderly” as frail, helpless, burdensome, and disposable. Those who are already socially isolated and lonely face even greater disconnect, as they are increasingly unable to interact with others outside the home.

This online survey focuses on the experiences, perspectives, and health of older Americans through the COVID-19 pandemic. The baseline survey will collect information on background demographics, living context, social networks, health status, and current impacts of the pandemic on daily life. Brief follow-up surveys emailed to participants bi-weekly will assess changes to health and well-being, and capture dynamic experiences and perspectives during the crisis. A subset of 20 participants who volunteer to be contacted for a semi-structured interview by telephone to share their stories and thoughts more in-depth.

Participants:

- Self-identify as an older adult (for IRB: age 55+)
- Reside in the United States (both community-dwelling and institutional)
- Internet access to participate in the online survey

BASELINE SURVEY

Hello!

Thank you for participating in the COVID-19 Coping Study. It will take approximately 20 minutes to complete this questionnaire.

ONLINE CONSENT FOR PARTICIPATION IN A RESEARCH STUDY UNIVERSITY OF MICHIGAN SCHOOL OF PUBLIC HEALTH

IRB: HUM00179632

Study Title: The COVID-19 Coping Study

Principal Investigators (the persons who are responsible for this research):

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Summary:

We are asking you to join a research study. The purpose of this study is to find out how the COVID-19 (coronavirus) pandemic is affecting the health and well-being of older adults in the United States. We hope to better understand older adults' experiences, perspectives, and ways of coping during the crisis.

Study activities will include completion of an online survey. We'd be grateful if you could also answer shorter follow-up surveys in the future about how things have changed.

It will take approximately 20 minutes to complete this survey.

There may be some risks from participating in this research. Some of the topics covered in this study may be sensitive. Your information will be maintained securely.

The study will have no direct benefits to you. That said, your participation will help to inform best practices about how to support quality of life and well-being of older adults during public health crises.

Taking part in this study is your choice. You can choose to take part, or you can choose not to take part in this study. You also can change your mind at any time. Whatever choice you make will not affect your relationship with the University of Michigan.

Why is this study being offered to me?

We are asking you to take part in a research study because we think you are able to provide opinions on this topic that are relevant to this research.

Who is paying for the study?

This study is funded by the principal investigators' personal research funds at University of Michigan School of Public Health.

What is the study about?

The purpose of this study is to learn about how older adults are impacted by the COVID-19 (coronavirus) pandemic.

Who is eligible for the study?

To participate in this study, you must:

- 1) Be an older adult (at least 55 years old)
- 2) Currently live in the United States
- 3) Have access to a computer, tablet, or smartphone to complete the survey

What are you asking me to do and how long will it take?

If you agree to take part, your participation in this study will involve completing this survey. We think that the study will take approximately 20 minutes of your time.

If you agree to also participate in the follow-up surveys, we will email you every 2-4 weeks with a brief questionnaire to ask about how things have changed. We think these surveys will take approximately 10 minutes of your time.

Are there any risks from participating in this research?

If you decide to take part in this study, you may experience distress over the nature of some of the questions. Please remember that you may stop answering questions at any point if you do not wish to proceed. The information you provide is confidential and will not be shared in connection to your name or other identifying information. We do not expect any risks from taking part in this study other than a possible loss of confidentiality.

How can the study possibly benefit me or others?

You will not benefit from this study. However, we hope your participation will add to our knowledge about and best practices for supporting older adults during public health crises.

Will I be paid for participation?

You will not be paid for participation in this study.

How will you keep my data safe and private?

All of your responses will be stored confidentially. Only the researchers involved in this study and those responsible for research oversight (such as representatives of the University of Michigan Institutional Review Board) will have access to any information that could identify you that you provide. We will store your information securely. When we publish the results of the research or talk about it in conferences, we will not use your name.

What if I want to refuse or end participation before the study is over?

Taking part in this study is your choice. You can choose to take part, or you can choose not to take part in this study. You also can change your mind at any time. Whatever choice you make will not have any effect on your relationship with the University of Michigan.

Who should I contact if I have questions?

Please feel free to reach out with any questions or concerns. If you have questions later or if you have a research-related problem, you can email or call either of the study investigators:

- Dr. Lindsay Kobayashi: lkob@umich.edu, 734-763-0322
- Dr. Jessica Finlay: jmfinlay@umich.edu, 734-647-0858

If you have questions about your rights as a research participant, or you have complaints about this research, you call the University of Michigan Institutional Review Board at (734) 936-0933 or email irbhsbs@umich.edu.

Documentation of Informed Consent

Your electronic signature below indicates that you read and understand this consent form and the information presented and that you agree to be in this study.

Please print or save this page for a copy of the informed consent.

Section I: Questions about you

1. What is the email address you would like us to use to send follow-up surveys? This information will NOT be shared with any third parties. *[open text box]*
2. How did you **first** hear about the COVID-19 Coping Study? *[Facebook; Twitter; from a family member, friend, or colleague; email list or message board [please state which one]; other [please state]]*
3. What is your year of birth? *[drop-down menu with options from 1965 to 1910]*
4. What is your sex? *[male, female, other, prefer not to answer]*
5. What race do you consider yourself to be? Please select all that apply.
[White; Black or African American; Middle Eastern or Arab American; Chinese; Filipino; Asian Indian; Vietnamese; Korean; Japanese; Other Asian (e.g. Pakistani, Cambodian, Hmong, etc.); Native Hawaiian or Other Pacific Islander; American Indian or Alaska Native; Other [please enter race or origin]]
6. Do you consider yourself Hispanic or Latino? *[yes, no]*
7. What is your relationship status? *[single, never married; single, divorced/separated; single, widowed; married or in a relationship; other]*
8. What is your highest level of educational attainment? *[no formal education; less than high school; high school diploma; high school equivalency (GED); some college; college graduate; post-college (e.g. Master's degree, MD, JD, PhD)]*
9. Before the COVID-19 (coronavirus) pandemic, how would you describe your employment status? *[In school; self-employed; part-time employment; full-time]*

employment; unable to work due to disability or health condition; homemaker or full-time family caregiver; unemployed and seeking work; retired]

10. What industry do you typically work in, or did you work in if you are retired or otherwise not working? *[open-ended]*
11. In your usual life, before the COVID-19 (coronavirus) pandemic, did you have any of the following regular caregiving responsibilities? Please select all that apply. *[elderly parent, grandparent, or relative; person with long-term conditions or disabilities; grandchildren; other; none of the above]*

Section II: Questions about the current impacts of the COVID-19 (coronavirus) pandemic

This section asks about your experiences and feelings related to the ongoing COVID-19 (coronavirus) pandemic.

12. How worried are you about the COVID-19 (coronavirus) pandemic? *[not at all worried; slightly worried; somewhat worried; moderately worried; extremely worried]*
13. Have you had COVID-19 (coronavirus)? *[yes, diagnosed with a test and recovered; yes, diagnosed with a test and still sick; not diagnosed or tested, but I have recently had a cough, fever, or other flu-like symptoms; no]*
14. Have any of your family members or friends had COVID-19 (coronavirus)? Please select all that apply, if needed. *[yes, diagnosed with a test and recovered. If yes, how many: [open text box]; yes, diagnosed with a test and still sick. If yes, how many: [open text box]; not diagnosed or tested, but they have recently had a cough, fever, or other flu-like symptoms. If so, how many: [open text box]; no] If yes → go #15; If no → go to #17*
15. How many of your family members or friends have been hospitalized due to COVID-19 (coronavirus) or COVID-19-like symptoms? *[open text box]*
16. How many of your family members or friends passed away due to COVID-19 (coronavirus) or COVID-19-like symptoms? *[open text box]*
17. How has your work been affected as a result of COVID-19 (coronavirus)? *[I have lost my job; I have been furloughed or placed on a leave of absence; I have reduced work hours/income; I am working from my home or another location; My work has not been affected] If #9 is no, #17 is skipped*
18. In the **past week**, how many days have you: *[response options for all: 0 days, 1-3 days, 4-6 days, 7 days]*

- a. Been self-isolating (i.e., not left your residence except for essential purposes such as work, obtaining food, medications, or other supplies, outdoor exercise, or taking care of pets)?
 - b. Been outside for 15 minutes or more?
 - c. Had in-person face-to-face contact with another person for 15 minutes or more (including someone you live with)?
 - d. Had a phone or video call with another person for 15 minutes or more?
 - e. Communicated with family, friends, and/or other people over text message, email, or other social media or messaging applications such as Facebook or WhatsApp?
19. In the **past week**, have any of these things been causing you significant worry or stress (e.g., constantly on your mind or keeping you awake at night)? Please select all that apply.
- a. Marriage or other romantic relationship
 - b. Friends or family
 - c. Neighbors
 - d. Your pet
 - e. Work (even if your job is safe)
 - f. Losing or lost work/unemployment
 - g. Everyday finances
 - h. Retirement savings
 - i. Getting medication and/or medical care
 - j. Getting food
 - k. Internet and/or computer access
 - l. Having nothing to do
 - m. Future plans
 - n. Concerns about your own health (not related to COVID-19)
 - o. Concerns about family or friends' health (not related to COVID-19)
 - p. Catching COVID-19
 - q. Becoming seriously ill from COVID-19
 - r. Family members or friends becoming seriously ill from COVID-19
 - s. Your own physical safety or security
 - t. None of the above
 - u. Other [please describe]
20. The next questions are about how you feel about different aspects of your life. For each one, please indicate how often you felt that way in the **past week**. [*response options for all: hardly ever; some of the time; often*]
- a. How often did you feel you lacked companionship?
 - b. How often did you feel left out?
 - c. How often did you feel isolated from others?
21. Now, think about the **past week** and the feelings you have experienced. Were any of the following true for you? In the past week, [*response options for all: yes; no*]
- a. much of the time, you felt depressed?
 - b. ... much of the time, you felt that everything you did was an effort?
 - c. ... much of the time, your sleep was restless?

- d. ... much of the time, you were happy?
- e. ... much of the time, you felt lonely?
- f. ... much of the time, you enjoyed life?
- g. ... much of the time, you felt sad?
- h. ... much of the time, you could not get going?

22. After each statement, please indicate how often you felt that way during the **past week**. The best answer is usually the one that comes to your mind first, so do not spend too much time on any one statement. *[response options for all: most of the time, some of the time, hardly ever, never]*

- a. I had fear of the worst happening.
- b. I was nervous.
- c. I felt my hands trembling.
- d. I had a fear of dying.
- e. I felt faint.

23. At any time in the **past week**, did you feel you had been treated poorly, threatened, or harassed? *[yes; no]* **If yes → go to #23a; If no → go to #24**

- a. If yes: what do you think were the reason(s) why these experiences happened to you? Please select all that apply. *[your ancestry or national origin; your gender; your race or ethnicity; your age; your financial status; other, please describe]*

24. To what extent do you agree or disagree with the following statements? *[response options for all: strongly agree, agree, neither agree nor disagree, disagree, strongly disagree]*

- a. I have received many offers of assistance from my community to help with daily life during social distancing measures or shelter in place orders.
- b. The federal government cares about the health and well-being of older adults in America.
- c. My state government cares about the health and well-being of older adults in my state.
- d. The level of respect for older adults in society has decreased during the coronavirus pandemic.

25. Over the **past week**, have any of your usual daily activities or behaviors changed? *[response options for all: more than usual; about the same as usual; less than usual; I don't normally do this activity]*

- a. Spending quality in-person time with family or friends
- b. Phoning or video calling family or friends
- c. Text messaging with family or friends
- d. Using online social media
- e. Watching or reading the news
- f. Watching TV or movies
- g. Practicing mindfulness
- h. Going outside
- i. Exercising
- j. Making homemade food

- k. Drinking alcohol
- l. Working on home projects
- m. Developing new routines or hobbies
- n. Helping others and/or volunteer
- o. Supporting local businesses
- p. Other, please describe

26. Are you taking any strategies that have been helping you to cope with the COVID-19 (coronavirus) pandemic? Please describe them below. *[open text box]*

Section III: Questions about your health

Next, we have some questions about your health.

27. How would you rate your **health** at the present time? *[excellent; very good; good; fair; poor]*
28. How would you rate your **memory** at the present time? *[excellent; very good; good; fair; poor]*
29. Has a doctor ever told you that you have any of the following medical conditions? Please select all that apply. *[high blood pressure; diabetes; heart disease; asthma; chronic obstructive pulmonary disease (COPD); cancer; other limiting, long-standing health condition]*
30. Do you use any mobility aids or equipment at the present time? Please select all that apply. *[cane; walker; wheelchair; motorized scooter; other]*
31. Do you smoke cigarettes? *[never smoked; ex-smoker; current smoker]*
32. Before the COVID-19 (coronavirus) pandemic, how many drinks of alcohol did you usually have per **week** (e.g. glasses of wine, beer, or shots of spirits/hard liquor)? *[drop-down menu for number: 0 through 10+]*
33. Before the COVID-19 (coronavirus) pandemic, how much moderate-to-vigorous exercise did you usually do per **week** (e.g., exercise for leisure, transportation, or housework that gets your heart rate elevated and makes you breathe faster)? *[drop-down menu 30-minute intervals from 0 minutes to 2.5 hours or more]*

Section IV: Questions about where you live

34. What is your zip code? *[short-box answer]*

35. What type of building do you live in? [*detached house; attached townhome; apartment or condominium; senior independent living; senior assisted living; nursing home; other*]
36. Which describes the residence you live in? [*owned outright; owned with the help of a mortgage; rented (market rental); rented (subsidized housing); living rent-free (e.g., with family members); other*] **If yes → go to #36a; If no → go to #37**
- a. If indicated rent or mortgage: Approximately how much is your monthly mortgage or rental payment? [*options from less than \$500 per month, to more than \$3000 per month, in \$500 intervals*]
37. Do you live alone? [*yes; no*] **If yes → go to #37a; If no → go to #38**
- a. If yes: Who do you live with? (check all that apply) [*Spouse/partner; children; grandchildren; other immediate family; friend; roommate; other*]
38. Usually in your life, how do you typically get to places outside your residence? Please select all that apply. [*walk; drive self in a car; get a ride with someone you know; taxi or rideshare; public transit; assisted mobility transit; bicycle; wheelchair or scooter; other*]

Section V: Questions about who you see and talk to

This final section of the survey asks about your usual social activities ("In your usual life...") before the COVID-19 (coronavirus) pandemic may have affected your daily life. Please answer openly and truthfully.

39. Do you have any living children or step-children? [*yes; no*] **If yes → go to #40; If no → go to #41**
40. In your usual life, how often do you do each of the following activities with your **children**, not counting any of your children that live with you: [*response options for all: three or more times per week; once or twice a week; once or twice a month; once every few months; once or twice year; less than once per year or never*]
- a. Meet in person (both arranged and chance meetings)
- b. Talk on the phone or video call
- c. Write, email, text message, or chat on social media
41. Do you have any other family, such as siblings, parents, cousins, nieces, nephews, or grandchildren? [*yes, no*] **If yes → go to #42; If no → go to #43**
42. In your usual life, how often do you do each of the following activities with these **family members**, not counting any of your family members that you live with: [*response options for all: three or more times per week; once or twice a week; once or twice a month; less than once a month*]

- a. Meet in person (both arranged and chance meetings)
 - b. Talk on the phone
 - c. Write, or email, text message, or talk on social media
43. Approximately how many friends do you have (not including family members)? *[drop-down with options of: 0; 1-3; 4-6; 7-9; 10+]* **If yes → go to #44; If no → go to #45**
44. In your usual life, how often do you do each of the following activities with **friends**, not counting friends that you live with: *[response options for all: three or more times per week; once or twice a week; once or twice a month; once every few months; once or twice year; less than once per year or never]*
- a. Meet in person (both arranged and chance meetings)
 - b. Talk on the phone
 - c. Write, or email, text message, or talk on social media
45. In your usual life, how often do you see and talk to your **neighbors**, not including those who you see as friends? *[three or more times per week; once or twice a week; once or twice a month; once every few months; once or twice year; less than once per year or never]*
46. In your usual life, do you receive **regular in-home assistance or care** from a family member or a professional, such as a care aide, cleaner, or certified nursing assistant? *[yes; no]*
47. In your usual life, how often do you participate in any **social organizations or clubs** (e.g., coffee group, walking or health/exercise club, civic group, volunteer group, religious or church group)? *[daily or almost daily; three to five times per week; once or twice a week; once or twice a month; once every few months; once or twice year; less than once per year or never]*
48. In your usual life, how often do you go on **social media** (such as Facebook, Instagram, Twitter)? *[daily or almost daily; three to five times per week; once or twice a week; once or twice a month; once every few months; once or twice year; less than once per year or never]*
49. In your usual life, do you have social contact as often as you would like? *[none of the time; a little of the time; some of the time; most of the time; all of the time]*

Wrapping up

50. Is there anything else that you would like to tell us about your experiences during the COVID-19 pandemic? *[large text box]*

FOLLOW-UP SURVEY

This survey asks about your experiences and feelings related to the ongoing COVID-19 (coronavirus) pandemic.

1. How worried are you about the COVID-19 (coronavirus) pandemic? [*not at all worried; slightly worried; somewhat worried; moderately worried; extremely worried*]
2. Have you had COVID-19 (coronavirus)? [*yes, diagnosed with a test and recovered; yes, diagnosed with a test and still sick; not diagnosed or tested, but I have recently had a cough, fever, or other flu-like symptoms; no*]
3. Have any of your family members or friends had COVID-19 (coronavirus)? [*yes, diagnosed with a test and recovered; diagnosed with a test and still sick; not diagnosed or tested, but they have recently had a cough, fever, or other flu-like symptoms; no*] **If yes → go to #4; If no → go to #6**
4. Have any of your family members or friends been hospitalized due to COVID-19 (coronavirus)? [*yes; no*]
5. Have any of your family members or friends passed away due to COVID-19 (coronavirus)? [*yes; no*]
6. Have you lost employment as a result of COVID-19 (coronavirus)? [*yes, I have lost my job; yes, I have been furloughed or placed on a leave of absence; yes, I have reduced work hours/income; yes, I am working from home now; no; N/A as I am retired or not working*]
7. In the **past week**, how many days have you: [*response options for all: 0 days, 1-3 days, 4-6 days, 7 days*]
 - a. Been self-isolating (i.e., not left your residence except for essential purposes such as work, obtaining food, medications, or other supplies, outdoor exercise, or taking care of pets)?
 - b. Been outside for 15 minutes or more?
 - c. Had in-person face-to-face contact with another person for 15 minutes or more (including someone you live with)?
 - d. Had a phone or video call with another person for 15 minutes or more?
 - e. Communicated with family, friends, and/or community members over text message, email, or other social media or messaging applications such as Facebook or WhatsApp?
8. In the **past week**, have any of these things been causing you significant stress (e.g., constantly on your mind or keeping you awake at night)? Please select all that apply.
 - a. Marriage or other romantic relationship
 - b. Friends or family
 - c. Neighbors
 - d. Your pet
 - e. Work (even if your job is safe)
 - f. Losing your job/unemployment
 - g. Everyday finances
 - h. Retirement savings
 - i. Getting medication and/or medical care
 - j. Getting food

- k. Your own safety/security
 - l. Internet and/or computer access
 - m. Boredom
 - n. Future plans
 - o. Concerns about your own health (not related to COVID-19)
 - p. Concerns about family or friends' health (not related to COVID-19)
 - q. Catching COVID-19
 - r. Becoming seriously ill from COVID-19
 - s. Family members or friends becoming seriously ill from COVID-19
 - t. None of the above
 - u. Other [please describe]
9. The next questions are about how you feel about different aspects of your life. For each one, please say how often you felt that way during the **past week**. [*response options for all: hardly ever; some of the time; often*]
- a. How often do you feel you lack companionship?
 - b. How often do you feel left out?
 - c. How often do you feel isolated from others?
10. Now, think about the **past week** and the feelings you have experienced. Are any of the following true for you? In the past week, [*response options for all: yes; no*]
- a. ... much of the time, you felt depressed?
 - b. ... much of the time, you felt that everything you did was an effort?
 - c. ... much of the time, your sleep was restless?
 - d. ... much of the time, you were happy?
 - e. ... much of the time, you felt lonely?
 - f. ... much of the time, you enjoyed life?
 - g. ... much of the time, you felt sad?
 - h. ... much of the time, you could not get going?
11. After each statement, please indicate how often you felt that way during the **past week**. The best answer is usually the one that comes to your mind first, so do not spend too much time on any one statement. [*response options: most of the time, some of the time, hardly ever, never*]
- i. I had fear of the worst happening.
 - ii. I was nervous.
 - iii. I felt my hands trembling.
 - iv. I had a fear of dying.
 - v. I felt faint.
12. In the **past week**, have you been treated poorly, threatened, and/or harassed? **If yes → go to #12a; If no → go to #13**
- a. If yes: what do you think were the reason(s) why these experiences happened to you? (check all that apply) [your ancestry or national origin; your gender; your race or ethnicity; your age; your financial status; your sexuality or sexual identity; other, please describe]
13. To what extent do you agree or disagree with the following statements? [*strongly agree, agree, neither agree nor disagree, disagree, strongly disagree*]
- a. I have received offers of support or assistance from my community to help with daily life during social distancing measures and/or shelter in place orders.
 - b. The federal government cares about the health and well-being of older adults in America.

- c. My state government cares about the health and well-being older adults in my state.
- d. The level of respect for older adults in society has decreased during the coronavirus pandemic.

14. Over the **past week**, have any of your usual daily activities or behaviors changed?
[response options for all: more than usual; about the same as usual; less than usual; I don't normally do this activity]

- a. Spending quality in-person time with family or friends
- b. Phoning or video calling family or friends
- c. Text messaging with family or friends
- d. Using online social media
- e. Watching or reading the news
- f. Watching TV or movies
- g. Practicing mindfulness
- h. Going outside
- i. Exercising
- j. Making homemade food
- k. Drinking alcohol
- l. Working on home projects
- m. Developing new routines or hobbies
- n. Helping others and/or volunteer
- o. Supporting local businesses
- p. Other, please describe

15. Are you taking any strategies that have been helping you to cope with the COVID-19 (coronavirus) pandemic? Please describe them below. *[open text box]*

16. How would you rate your **health** at the present time? *[excellent; good; very good; good; fair; poor]*

17. How would you rate your **memory** at the present time? *[excellent; good; very good; good; fair; poor]*

18. Is there anything else that you would like to tell us about your experiences during the COVID-19 pandemic? *[large text box]*