AN EXPLORATORY ANALYSIS OF NEXT OF KIN DATA IN COVID-19 DEATHS

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ABSTRACT

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Objective: This thesis aims to: 1) conduct a formative evaluation of the next of kin (NOK) interview data collected during the Michigan COVID-19 Death Investigation (MiCOVDI); 2) investigate the prevalence of proxy-reported health care discrimination experienced by those that died from COVID-19 in Michigan during March 3-July 26, 2020. **Methods:** Decedents were eligible for inclusion in the mortality review if COVID-19 was listed as an underlying or related cause of death on the death certificate. A stratified random sample of deaths was taken and NOK interviews were conducted via telephone. The completeness of the dataset was assessed to evaluate feasibility and validity. NOK-reported discrimination in decedent's COVID-19 testing and care was described and compared by attributes of the decedent and NOK using univariate statistics. Qualitative interview responses were used to elaborate on the NOK's understanding of the decedent's experience. **Results:** The overall prevalence of NOK-reported health care discrimination experienced by the decedent was 28% with no strong associations with decedent or NOK attributes. The majority of reported discrimination was age- (20%) or comorbidity-based (27%). The prevalence estimates of situation-specific discrimination were: doctor's office (2%), urgent care (12%), COVID-19 testing (13%), being hospitalized (14%), and at an emergency room (18%). The overall completeness of the MiCOVDI survey was 59%. Completeness did not differ by race. **Conclusion:** Mortality reviews shed light on systematic issues experienced by those that passed away from COVID-19 and may inform targets that improve health equity. Examining the completeness of these data can provide insight to improve future endeavors.

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KEY TO ABBREVIATIONS

COVID-19	Coronavirus disease 2019
NOK	Next of kin
MiCOVDI	Michigan Coronavirus Disease 2019 Death Investigation
MDHHS	Michigan Department of Health and Human Services
NIH	National Institutes of Health
CDC	Centers for Disease Control and Prevention

INTRODUCTION

COVID-19 Background

Since being declared a pandemic by the World Health Organization on March 11, 2020[1], COVID-19 continues to impact the lives of millions. As of August 2022, there have been 6.4 million deaths globally, with over 1,000,000 deaths occurring in the United States alone.[2] There have been 90 million confirmed COVID-19 cases in the United States, which amounts to 27% of the population.[2] There remains an urgent need for research on this novel disease and its impacts. Furthermore, it is imperative that the research processes and public health programs designed to investigate and/or manage COVID-19 are formally evaluated.

Throughout the entirety of the pandemic, it has been apparent that COVID-19 infection does not impact all people equally. There are disparities in both disease severity and mortality among different groups.[3] Disease severity refers to the impact of disease in an individual and consists of the following categories: asymptomatic, mild, moderate, severe, and critical illness.[4] Risk factors for COVID-19 disease severity and mortality include increasing age, the presence of comorbidities, male sex, and African American or Native American race/ethnicity.[3] Common comorbidities linked to an increased risk for COVID-19 mortality include cancer, chronic kidney disease, chronic lung diseases, dementia, diabetes, and heart conditions such as heart failure or coronary artery disease.[5] Age/sex/race disparities may be in part due to a higher prevalence of comorbidities leading to increased risk of severe COVID-19 infection or death , as is seen in the Black population[6], or social factors that inherently increase risk for infection (i.e., essential worker as employment or living in high-density neighborhoods).[6] However, discrimination in health care is a prevalent problem in the United States that may be perpetuating these disparities.[7,8]

Health Care Discrimination

Investigating health care discrimination as it relates to obtaining COVID-19 care may provide insight into the disparities seen for COVID-19 disease severity and mortality. The National Institute of Health (NIH) defines discrimination as "actions, based on conscious or unconscious prejudice, which favor one group over others in the provision of goods, services, or opportunities".[9] Discrimination can be broken down into two main levels: structural/institutionalized and interpersonal/personally-mediated discrimination.[10,11] Structural discrimination is defined by the NIH as "macro-level conditions that limit opportunities, resources, power, and well-being of individuals and populations based on race/ethnicity and other statuses".[11] In the context of health care discrimination, this may manifest as unequal access to hospitals or policies that put certain groups at a disadvantage.[10,11] Interpersonal discrimination occurs when one generates an assumption about another based on their race, sex, age, or some other characteristic, that leads to differential treatment.[10] In the context of health care, this type of discrimination often occurs at the patient/provider level and can take many different forms.[12] For example, discrimination at this level may stem from personal biases of health care providers and lead to inferior care, lack of respect, and miscommunication.[13] Patients report that they are most commonly discriminated against because of their race/ethnicity, education/income, weight, sex, or age.[14] Given that health care discrimination is associated with factors related to COVID-19 mortality (race, sex, age, income)[3,5,15], and can lead to inferior care[13], investigating discrimination prevalence among those obtaining COVID-19 care prior to death is essential. Understanding potential discrimination experienced by decedents prior to death may provide insight into the disparities seen in COVID-19 mortality. For example, the

racial disparities may be in part explained by inferior care received at hospitals due to discrimination.

Health care discrimination is a self-reported measure that has been operationalized in the literature multiple ways. In a national survey conducted by Nong et al., a mixed methods technique was used.[14] Participants were asked whether or not they had ever experienced discrimination, followed by a question offering categorical reasons for the discrimination (i.e., race, age, sex) to choose from.[14] An open-ended option was available to elaborate, and the frequency of discrimination was asked last.[14] Rogers et al. operationalized health care discrimination as a series of questions requesting categorical responses.[16] Questions such as the following were used: "How often do you receive poorer service or treatment than others from doctors or hospitals?" and "How often are you treated with less courtesy or respect?".[16] The possible answers provided to participants included measures of frequency, such as "less than once a year" or "a few times a year".[16] On the other hand, D'Anna et al. operationalized discrimination as a series of eight open-ended questions.[17] The interview focused on topics such as phrases health care providers say that may be perceived as discriminatory, aspects of medical care that are unfair, and reasons for and examples of being discriminated against.[17]

There is evidence supporting the notion that health care discrimination is a prevalent problem in the United States. A survey of U.S. adults found that one in five participants have experienced some health care discrimination, with 72% of those reporting more than one occurrence of discrimination.[14] The most commonly reported type of discrimination was racial (17%), followed by income-based (12%), sex-based (11%), and age-based (10%).[14] Discrimination based on insurance status and drug use were also reported.[14] A study of health care discrimination in adults over the age of 50 discovered that 20% of participants experienced

health care discrimination, corroborating the results reported by Nong et al..[14,16] Ageism is an important contributor to the discrimination prevalence. A survey of adults over age 50 found that 28% of participants experienced ageism in the health care system.[16] Rogers et al. reports that health care discrimination is associated with adults developing a new or worsened disability such as high blood pressure, cancer, or diabetes.[16] This further supports the idea that health care discrimination may lead to inferior treatment and negatively impact patient health.[13] D'Anna et al. conducted a qualitative study of health care discrimination and discovered patient-level, provider-level, and systemic factors to be associated with reporting discrimination.[17] Some of these factors include the patient's race/ethnicity, diagnosis, and native language, along with the provider's communication skills and attitude towards staff members.[17] Systemic factors reported by Danna et al. that may perpetuate discrimination include access to treatment, insurance coverage, and lack of standardized care at clinics.[17]

Resources for testing, emergency care, and effective treatments were all limited during the early period of the pandemic in 2020 (i.e., March – July 2020). Regarding COVID-19 testing, a U.S. survey found that only 50% of participants with COVID-19 symptoms between July, 2020 – September, 2021 received a diagnostic test for COVID .[18] Authors note that the lack of testing was most prominent during the early pandemic and may have been due to lack of resources and/or providers using the few available tests on only high-risk or severely ill patients.[18] Further complicating resource allocation during the pandemic's first wave was the fact that effective treatments for COVID-19 were not available.[19] Clinicians, public health officials, and governmental agencies were attempting to create recommendations and distribute scarce resources for a disease that little was known about.[19]

While discrimination can occur even when resources are abundant, biases are more likely to impact access of care when resources are limited.[20] Overwhelmed hospitals and scarcity of testing and equipment created the need to ration resources, which may have put those already in poor health at a disadvantage.[20,21] As poor health is more common among groups at high risk for COVID mortality (i.e., Black, elderly, and those suffering from comorbidities), double jeopardy ensues. For example, Riviello et al. assessed equipment rationing practices in hospitals and found that Black patients were more likely to be considered low priority than White patients, thus making them less likely to receive scarce resources such as ventilators.[22] Physicians determined a patient's priority status by considering the Sequential Organ Failure Assessment (SOFA) score of the patient, alongside their comorbidities and likelihood for both short- and long-term survival.[22] De Castro-Hamoy et al. describes the concern that age may have been used as a reason to deny elderly patients scarce resources, rather than considering their medical history as a whole before making a decision.[23] Having to "rank" patients based on illness severity and medical history can raise the opportunity for biases to enter a provider's decision making, whether it be due to age, race, sex, or preexisting conditions.[22]

Michigan COVID-19 Death Investigation

One source of data that could be used investigate discrimination in health care as it relates to COVID-19 is the Michigan COVID-19 Death Investigation (MiCOVDI). This program began during the first wave of the pandemic at the Michigan Department of Health and Human Services. The goal of this program is to identify underlying factors that relate to the risk of COVID-19 death. Specifically, this project is designed to detect potential systems issues that relate to COVID-19 mortality, such as disparities in obtaining testing and health care prior to

death. Using the information gained from this project, MDHHS will provide recommendations to reduce COVID-19 mortality. The original emphasis of MiCOVDI was to investigate racial discrimination as it pertains to obtaining COVID-19 health care. Decedents were considered eligible for inclusion in the mortality review sample if COVID-19 was documented as an underlying or related cause of death on their death certificate. Next of kin (NOK) were then contacted via telephone, from whom information was gathered on sociodemographic and health-related characteristics of the decedent. In addition, information on perceived discrimination experienced by the decedent in obtaining COVID-19 testing and/or care prior to death was reported by the NOK.

Proxy Respondents in Health Care

Just two studies have examined NOK or proxy interviews in relation to COVID-19 mortality, focusing on the importance of communication between health care staff and next of kin throughout the decedent's hospitalization for and death from COVID-19.[24,25] Both studies used next of kin interviews conducted in 328 deaths among United States Veterans.[24,25] The mean age of decedents in the study population was 77 years old, and made up almost entirely of males (96%).[24,25] The race/ethnicity distribution was 47% non-Hispanic White and 51% all other race/ethnicities.[24,25] Results of both studies showed that good communication between health care staff and family members was associated with families reporting a more positive experience.[24,25] Esrek et al. quantified the relationship between good communication and reporting positive experiences, whereas Feder et al. investigated the open-ended responses of the interviews.[24,25] However, unlike the MiCOVDI NOK interviews, sociodemographic

characteristics of the decedent were not examined within the context of the reported health care experience, and proxy-reported discrimination was not discussed.

While the literature may be limited on NOK reporting specific to COVID-19, there is a considerable body of research published on proxy respondents in the context of other medical conditions. Proxies are commonly used in situations with the elderly or very young, specifically when the patient is unable to provide written and/or oral feedback. There are numerous conditions for which proxies are commonly used, such as cancer, stroke, and Alzheimer's disease.[26–29]

The content area of study and relationships between the proxies and the targeted respondent are two areas of frequent study in assessing the quality of information. The validity of proxy responses has been found to vary widely with the content area, but there is insufficient literature on proxy reporting to conclude which content and from whom information can be reliably reported. When examining the agreement between proxy and patient reports related to mental health in a study of stroke patients and their proxy respondents, agreement was fair for depression and feelings of optimism and moderate for spirituality.[26] In a study examining cancer patients and proxy reporting on health behaviors, agreement varied by the specific behavior assessed.[30] For example, the percent agreement reported for smoking status was relatively high at around 80%, but agreement was much more inconsistent when assessing dietary habits, ranging from 54% to 82%.[30] Regarding proxy-reported health care experiences, two studies found that proxy respondents are more likely to report a less positive experience compared to self-reports by the patient.[31,32] In an assessment of the use of proxies in health research in older age populations, researchers reported that proxies tend to more accurately report on physical health and cognition as opposed to psychosocial health.[33] Taken together, these studies can only suggest

areas where proxy reporting seems acceptable. However, this area of research has been relatively neglected.

The relationship of the proxy to the patient may also play a role, with research showing spouses/partners tend to report experiences that are more positive and closer to the patient's self-report than other proxies.[32,34] Additionally, it has been reported that children acting as proxies tend to report worse experiences than spouses.[34] The involvement of the proxy in the patient's medical care can influence responses, with those who never attend medical appointments being more likely to report a worse experience with the health care system .[34]

Research assessing the reliability of proxy reports in death investigations finds mixed results and varies with the content being assessed. Halanych et al. examined the reliability of proxies in reporting decedent cause of death, and reported a moderate degree of agreement (kappa=0.69).[35] Niu et al. assessed proxy reliability of reporting decedent loneliness prior to suicide, and reported poor reliability (intraclass correlation coefficient =0.45).[36] Klinkenberg et al. examined the reliability of NOK reports on decedent symptomology and comorbidities, as compared to physician reports.[37] Regarding comorbidity presence, agreement varied based on condition, with the kappa value ranging from 0.23 to 0.75.[37] NOK reliability for decedent symptomology was higher, with the kappa value ranging from 0.52 to 0.81 depending on the symptom examined.[37] In addition to the need for assessment of proxy reliability overall, assessing these data within the context of death investigations has been an under-researched area. Given that the MiCOVIDI project relies heavily on NOK responses, evaluating the feasibility and validity of this data is of great importance.

As the COVID-19 pandemic continues, so does the MiCOVDI project. My evaluation of this data collected during the first wave of the pandemic may provide results that can be applied

to data collected during later waves. This involves investigating the quality of the data that can be obtained through NOK interviews. This will be done by assessing the completeness of the MiCOVDI survey. The second component of my thesis is an investigation of the discrimination experienced by the decedent, as reported by the NOK, in obtaining COVID-19 testing and health care prior to death. Additionally, the prevalence of reported discrimination in testing and care will be described and compared by attributes of the decedent, such as gender, race, and geographic region. My thesis assesses NOK-reported discrimination in health care in relation to COVID-19 mortality, and in so doing, it may inform intervention targets that improve health equity.

Thesis Aims and Hypotheses

Aim 1: conduct a formative evaluation of the next of kin (NOK) interview data collected during the Michigan COVID-19 Death Investigation (MiCOVDI).

Approach: Assessment of the completeness of the survey responses by calculating the missingness of the data overall, and by interview section. Determine whether or not missingness of data varies by interview topic or decedent race.

Aim 2: investigate the prevalence of proxy-reported health care discrimination experienced by those who died from COVID-19 in Michigan during March 3, 2020 – July 26, 2020.

Aim 2a: Investigate associations between proxy-reported health care discrimination and NOK and decedent attributes.

Hypothesis: There will be evidence of proxy-reported health care discrimination that occurred during the first wave of the pandemic. Reporting discrimination may be associated with decedent race and gender, which are known to be associated with both

COVID-19 mortality and discrimination. NOK relationship to the decedent may be associated with reporting discrimination, as literature shows a proxy's relationship to the patient impacts how the health care experience is perceived. Children will be more likely to report discrimination than spouses.

METHODS

MiCOVDI Project Overview

The Michigan COVID-19 Death Investigation was undertaken by the Michigan Department of Health and Human Services and Michigan State University to better understand factors related to COVID-19 mortality. Specifically, health disparities and system issues that may contribute to COVID-19 mortality risk were investigated. This project was funded by MDHHS through federal COVID funding allocations. The principal investigators of the NOK interview portion of the project are Kenneth Rosenman, M.D., of MSU's College of Human Medicine, and Dawn Misra, Ph.D., of MSU's Department of Epidemiology & Biostatistics.

MiCOVDI Sampling Methods

Deaths related to COVID-19 that occurred among Michigan residents between 3/2/20 and 7/26/20 were eligible for inclusion in the first wave of the mortality review. Sampling was conducted based upon: 1) three geographical regions of residence at the time of death: city of Detroit, out tri-country (Macomb, Oakland, and Wayne county [without Detroit]), and all other Michigan counties, and 2) three time periods: pre-peak (March 2- March 9), peak (March 30 – May 10), and post-peak (May 11 – July 26). Peak refers to the 2020 spring/summer COVID peak as determined in later summer 2020. The distribution of COVID-19 deaths across these nine strata was calculated from resident death file information provided by the MDHHS Division for Vital Records and Health Statistics. A stratified random sample of 100 deaths based on the percentages of deaths in each of the nine strata were selected for inclusion in the mortality review. Because COVID-19 significantly impacted Detroit early in the pandemic, and the goal of MiCOVDI was to detect racial disparities in obtaining care prior to death, cases were

oversampled for this geographical location. The sample for Detroit was 1.5 times larger than if the sample was based on the proportion of deaths in this stratum alone. The sampling weights are depicted in Table 1 below. The original sampling distribution is as follows (n=100): 4 pre-peak, 30 peak, and 4 post-peak cases from the city of Detroit; 2 pre-peak, 34 peak, and 5 post-peak cases from out tri-county; 1 pre-peak, 14 peak, and 6 post-peak cases from all other Michigan counties. Medical abstractors conducting case reviews decided to move certain cases to different regions based on where the decedent obtained medical care. For example, a decedent from Detroit receiving medical care in the out tri-county was considered an out tri-county case. The final sampling distribution (n=100) is as follows: 28 cases from Detroit, 48 cases from out tri-county, and 24 cases from all other Michigan counties (Table 1).

The following MiCOVDI data collection process is depicted in Figure 1. Medical records were obtained for 92 of these cases, and 89 of the records contained NOK information. The NOK information for the remaining three cases with medical records was gathered from death certificates.

There were eight cases in which the decedents' medical records were not obtained. NOK contact information was gathered from the death certificate in seven of these cases, and in one case, no NOK information could be found. Among NOK for whom we had obtained contact information (n=99), we were unable to reach NOK in 30 cases, were refused by NOK in 14 cases, and were able to obtain an NOK interview in 55 cases. Thus, 55 next of kin among the 100 deaths sampled agreed to participate in the interview. Figure 2 displays the MiCOVDI sampling process based on geographical region. The response rates varied by geographical location, with Detroit having the lowest (29%), followed by all other counties (50%), and the tri-county region (73%). Even though the city of Detroit was oversampled, decedents from that location remain

underrepresented in our sample. Inability to reach the NOK was the most common reason for nonresponse in Detroit (70%), out tri-county (77%), and all other counties (50%).

Table 1. Michigan COVID-19 Death Investigation original sampling weights

	Total COVID-19 Deaths in Michigan, 3/2/20 – 7/26/20 N=5,819								
	City of Detroit N=1,423			**Out Tri-County N=2,919**			**All other counties N=1,477**		
Pandemic phase*	1	2	3	1	2	3	1	2	3
# deaths	130	1,187	106	155	2,380	384	51	970	456
Sampling weights	2.2	20.4	1.8	2.7	40.9	6.6	0.9	16.7	7.8
Original sample	4	30	4	2	34	5	1	14	6
Final sample	28			48			24		

*Pandemic phase: 1= pre-peak, 3/2/20 – 3/9/20; 2=peak, 3/30/20 – 5/10/20; 3=post-peak, 5/11/20 – 7/26/20

Figure 1. Michigan COVID-19 Death Investigation data collection process

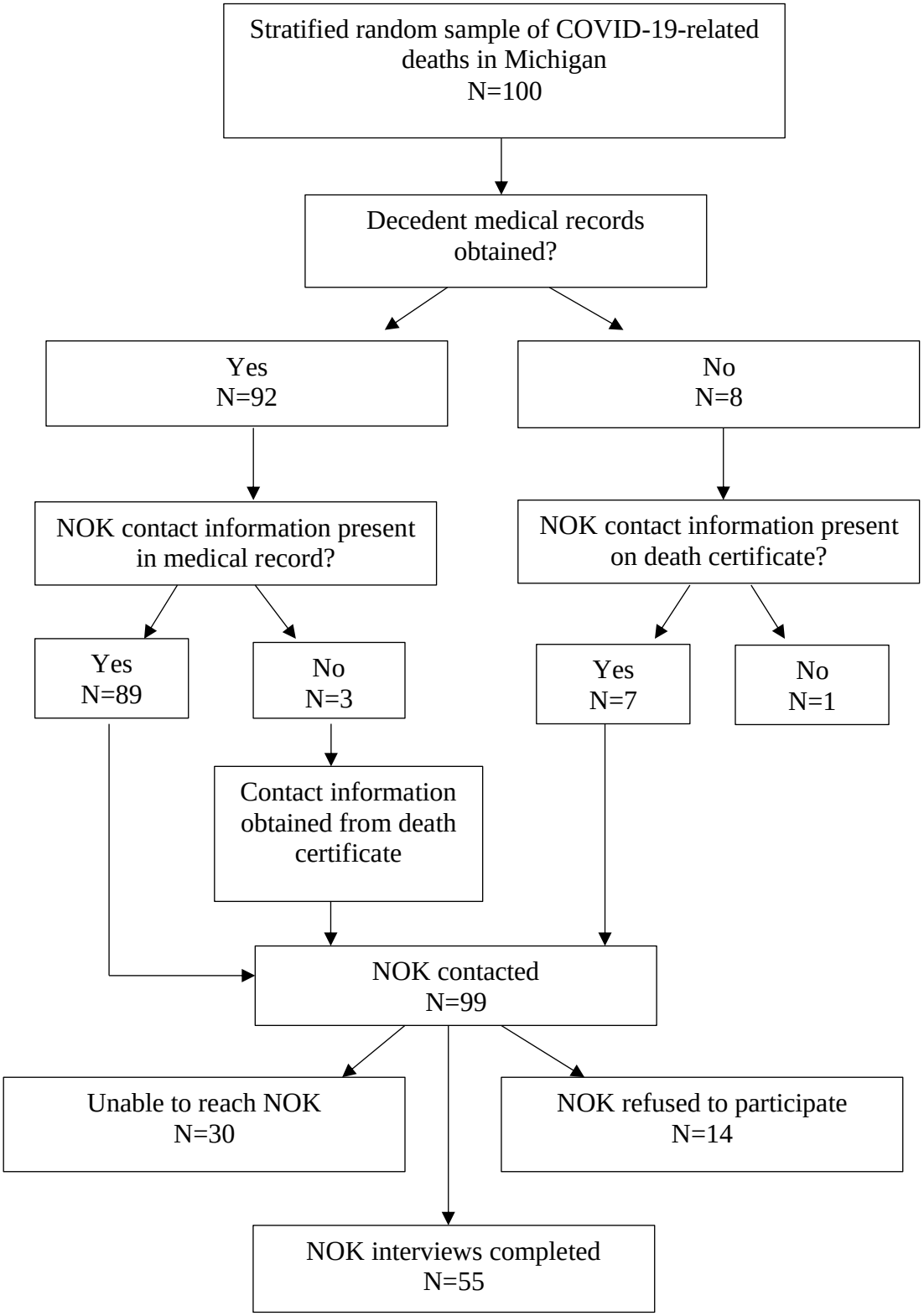
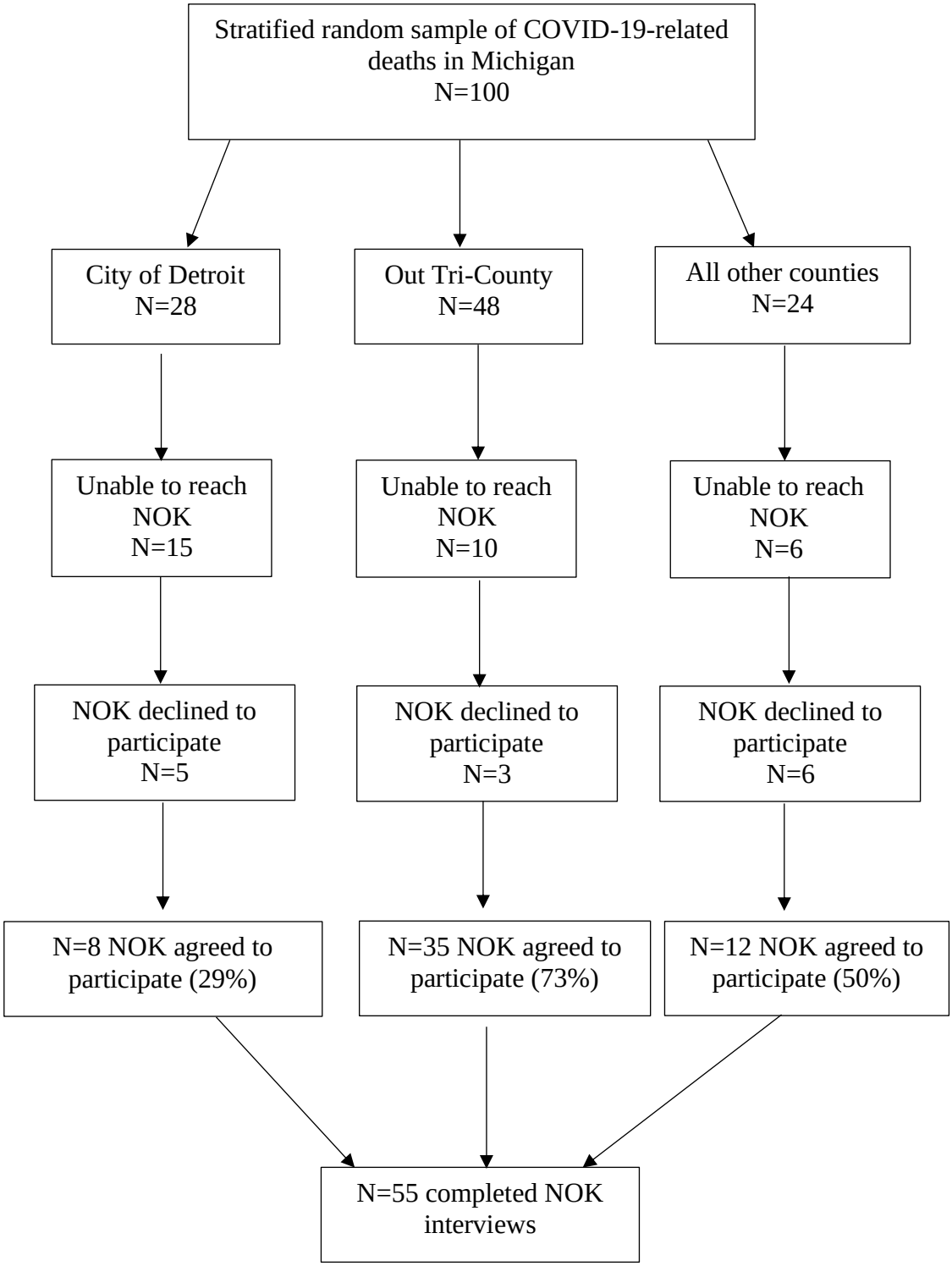


Figure 2. Final Michigan COVID-19 Death Investigation sampling schematic



MiCOVDI Data Collection

Qualified case abstractors employed by the Michigan Department of Health and Human Services were responsible for reviewing medical records and death certificates of those eligible for inclusion. Trained interviewers from Michigan State University were responsible for conducting the NOK interviews. Interviewers were experienced in survey data collection, and understood the sensitive nature of the MiCOVDI project. The interview consisted of a combination of closed- and open-ended questions, with a total of 120 questions. The questions used to collect data on health care discrimination, our primary outcome, are shown here:

1. *Do you think [the deceased] was treated differently from others or experienced discrimination **in trying to or obtaining COVID-19 testing**? For example, was testing denied or was delayed at any point you know about.*
2. *Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at **a doctor's office**? For example, was [the deceased] denied care or was care delayed or inadequate?*
3. *Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at **urgent care**? For example, was [the deceased] denied care or was care delayed or inadequate?*
4. *Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at **emergency room care**? For example, was [the deceased] denied care or was care delayed or inadequate?*
5. *Do you think [the deceased] was treated differently from others or experienced discrimination in **being hospitalized** for COVID-19? For example, was [the deceased] denied care or was care delayed or inadequate?*

Responses were read by two independent researchers and translated into the following categorical responses. The interrater reliability was 100%:

1: Yes, discrimination experienced

2: No discrimination experienced

3: NOK doesn't know

4: Not applicable

. : Missing

In cases where discrimination was reported, the qualitative text of the interview was read to determine if the type of discrimination (i.e., ageism, racism) could be discerned.

A list of all questions used in this study and their coded responses can be found in the Appendix (Table A1). All data in this study comes from the NOK interviews. The NOK interviews were conducted via telephone and ranged in duration of time. Dependent upon the length of the NOK's open-ended responses, the interview took anywhere from 45 minutes to an hour and a half.

Study Population

The dataset had a sample size of 55 and was de-identified upon receipt. In the NOK interviews, decedent race/ethnicity was categorized into eight groups based on NOK responses. For the purposes of this analysis, race was recoded as a two-level variable consisting of non-Hispanic Black and non-Hispanic White. The non-Hispanic Black group consisted of participants who reported a race/ethnicity of Black (n=16), Black & other (n=1), or American Indian/Alaska Native & Black (n=2). The non-Hispanic White category consisted of participants who reported a race/ethnicity of White (n=28), White & other (n=1), Middle Eastern or North African (n=2),

American Indian/Alaska Native & White (n=1), or other (n=2). Genders of the NOK and decedents were not asked as a part of the interview process. Qualitative text was read for each participant to determine the genders.

Statistical Analysis

First, we report descriptive results of the study sample, including sociodemographic and health-related characteristics of the decedent. In order to evaluate the feasibility and validity of these data, the completeness of the survey responses was examined. The interview consisted of 83 questions that were broken down into a total of 120 questions/sub-questions for this analysis (see Appendix Table A1). Responses of "missing" or "don't know" were considered missing, as neither of the responses provide information about the decedent. Responses of "yes" or "no" were considered complete. In situations where the response was "not applicable", the observation was excluded from the completeness analysis on that particular question (i.e., dropped from the denominator). Completeness percentages were calculated for the entire NOK interview, as well as by interview section.

Based on our aims, we further examined prevalence of COVID-19 testing and NOK-reported discrimination, which in part involved the analysis of qualitative data. This included whether or not the NOK perceived any discrimination was experienced by the decedent at the following times: at a doctor's office, at an urgent care, at the emergency room, in being hospitalized, or in obtaining COVID-19 testing. In addition to analyzing data from these questions, we created a dichotomous outcome variable for discrimination called "any discrimination". If the NOK reported discrimination in any of the previous situations, then the dichotomous discrimination variable was coded as "yes". The dichotomous discrimination

variable was coded as “no” if the NOK did not report discrimination in any of the five situations. The prevalence of any and specific domain NOK-reported discrimination was examined within the context of both decedent and NOK attributes. This involved describing and comparing reported discrimination by the decedent’s race, gender, and region of residence, as well as the NOK’s gender and relationship to the decedent. Chi-square tests of independence, or Fisher’s exact test where applicable, were conducted to determine whether or not reported discrimination was associated with the previously listed characteristics. Additionally, logistic regression was utilized to determine the magnitude and direction of these associations through odds ratios and 95% confidence intervals. These analyses were performed using SAS software, version 9.4. The NOK interviews contained open-ended, qualitative responses that were not used in the aforementioned statistical analyses. These responses regarding perceived discrimination were used to elaborate on the NOK’s understanding of the decedent’s experience. Qualitative responses were read to determine the prevalence of different types of discrimination reported in the sample (i.e., age and racial discrimination).

MDHHS owns the data. A data use agreement was entered by all parties involved. Because this study involves the analysis of de-identified, previously collected survey data, it was deemed not human research by Michigan State University’s Institutional Review Board.

RESULTS

Table 2 displays sociodemographic and health-related characteristics of the decedents for whom we were able to interview the NOK (n=55). Sixty-four percent of decedents were of non-Hispanic White race/ethnicity and 36% were non-Hispanic Black. The majority of decedents (76%) were over the age of 65 at the time of death, and the mean age in the sample was 74.3 years. Slightly more than half (56%) of decedents were male. When examining the geographical distribution of the sample with NOK data (n=55), we see that 14% of decedents were from the city of Detroit (n=8), 64% were from out tri-county (Macomb, Oakland, and Wayne counties, n=35), and 22% were from all other counties (n=12). Recall that the sample of deaths selected 38 deaths (38%) from Detroit and 62 from the other areas (tri-county and all other counties combined, 62%). Therefore, the NOK sample underrepresents decedents from Detroit compared to the full sample. The NOK response rate for Detroit decedents was much lower (21%, 8/38) than the proportion of NOK interviews for decedents in the other areas (76%, 47/62). Therefore, despite over-representing Detroit based on the proportion of COVID-19 deaths in the sampling approach, Detroit is not well represented in the NOK interview data. Since death certificate data was not available for this analysis, sociodemographic data on the 45 nonrespondents could not be examined.

More than two-thirds of the decedents were not in the workforce at the time of death, with retirement (64%), nursing home (20%), and disability (9%) being the most commonly cited reasons for not working. The yearly income of those in the sample ranged from $0 - $275,000 per year, with a median of $21,600. Among 53 NOK that answered questions regarding the decedent's health insurance status, all reported the decedent was covered by insurance. The majority of the sample (60%) was covered by Medicare. Comorbidities in the sample were

prevalent with the following distribution: 47% diabetes, 36% high blood sugar, 34% heart disease, 19% dementia, 18% high cholesterol, 15% COPD/emphysema/asthma, 10% cancer, and 7% kidney disease. Some decedents had multiple morbidities (70%), and most had at least one morbidity (91%).

Table 2. Sociodemographic and health-related characteristics of decedents in the Michigan COVID-19 mortality review sample (n= 55)

Michigan COVID-19 Mortality Review Sample Max N=55	N	(%)
Sociodemographic Characteristics		
Race/ethnicity*		
Non-Hispanic White	34	(64)
Non-Hispanic Black	19	(36)
Age (years)	Mean (SD)	Range
	74.3 (15.0)	36.5 – 102.9
< 35	0	(0)
35-49.9	5	(9)
50-64.9	8	(15)
65-79.9	22	(40)
80-94.9	17	(31)
95+	3	(5)
Gender		
Male	31	(56)
Female	24	(44)
Region		
Detroit	8	(14)
Out Tri-County	35	(64)
Other County	12	(22)
Employment Status*		
Working	9	(29)
Not Working	44	(71)
Reason for Not Being in Workforce*		
Retired	28	(64)
Nursing home	9	(20)
Homemaker	2	(5)
Disabled	4	(9)
Other	1	(2)
Yearly Income (USD)*	Median	Range
	$21,600	$0 - $275,000

Table 2. (cont'd)

Health Insurance*		
Yes	53	(100)
No	0	(0)
Health Insurance Plan*		
Medicare	32	(60)
Other	20	(37)
Don't Know	2	(3)
NOK-Reported Medical History		
Diabetes*		
Yes	25	(47)
No	26	(49)
Unsure	2	(4)
High blood sugar*		
Yes	19	(36)
No	28	(53)
Unsure	6	(11)
COPD/Emphysema*		
Yes	8	(15)
No	44	(83)
Unsure	1	(2)
Asthma*		
Yes	8	(15)
No	44	(83)
Unsure	1	(2)
Heart disease*		
Yes	18	(34)
No	30	(57)
Unsure	5	(9)
High cholesterol*		
Yes	18	(34)
No	26	(49)
Unsure	9	(17)
Dementia*		
Yes	19	(36)
No	32	(60)
Unsure	2	(4)
Cancer*		
Yes	10	(19)
No	42	(79)
Unsure	1	(2)
Kidney Disease*		
Yes	7	(13)

Table 2. (cont'd)

No	40	(76)
Unsure	6	(11)

* Missing Data: Race/ethnicity (N=2); Employment status (N=2); Yearly income (N=22); Health insurance (N=2); Health insurance plan (N=2); Reason for unemployment (N=11); Diabetes (N=2); High cholesterol (N=2); Heart disease(N=2); Dementia (N=2); Cancer (N=2); High blood sugar (N=2); Kidney disease (N=2); COPD/Emphysema (N=2); Asthma (N=2)

Tables 3 and 4 examine the completeness of NOK-reported data obtained during the Michigan COVID-19 mortality review among the 55 NOK interviews that were conducted. Overall, the completeness was 59%. The majority of the missing data was due to true missing responses (82%), while the remaining 18% of missing data was due to NOK responses of "don't know". Sections of the NOK interview with the highest completeness involved demographic information on the decedent such as region of residence (100%), gender (100%), and race/ethnicity (96%) as well as NOK demographics such as gender (93%) and relationship to the decedent (100%). Assessing NOK-reported discrimination dichotomously led to a high average completeness (98%), but when examining perceived discrimination within clinical setting types (e.g., emergency room), this average fell to 54% (range: 8 to 77%). The clinical setting-specific discrimination completeness did not vary by race, with NOK of White and Black decedents having very similar overall completeness percentages on these sections (55.8% vs. 54.1%, respectively) (Table 4). Sections of the NOK interview with low completeness included those that asked more detailed questions about the decedent's life and health care, such as medical care received prior to death (56%), yearly income (56%), and specific COVID-19 symptoms experienced (51%).

Table 3. Completeness[1] of data obtained during the Michigan COVID-19 mortality review

Michigan COVID-19 Mortality Review NOK Interview
N=120 questions assessed

	Completeness (%)
Overall (N=120 questions)	59%
Any perceived discrimination (Y/N)	98%
Perceived discrimination at specific locations (i.e., urgent care, doctor's office)	54%
Did the decedent visit these locations 14d prior to death (Y/N)	94%

Table 3. (cont'd)

# of times decedent visited each location 14d prior to death	10%
Symptomatic prior to death (Y/N)	93%
Specific symptoms experienced	51%
COVID-19 testing	51%
Medical care received before death	56%
NOK descriptions of health care experience	84%
Past medical care	32%
Height and weight of decedent	90%
Place of death	96%
Timing of death relative to hospital arrival	18%
Insurance coverage	84%
Comorbidities	90%
Employment of decedent	47%
Drug use (Y/N)	91%
Drug use specifics	10%
Race/ethnicity	96%
Yearly income of decedent	56%
# people in decedent's household	64%
COVID-19 status of those that lived with decedent	91%
Decedent's region of residence	100%
Decedent's gender	100%
NOK's gender	93%
NOK relationship to decedent	100%

[1] Complete data defined as responses of "yes", "no", or a non-missing qualitative response. Missing data defined as responses of "missing" or "don't know" . Individuals' responses to questions that were designated not applicable were removed

Table 4. Completeness of data on perceived discrimination reported by the NOK for the following clinical settings by decedent race

	Completeness of Discrimination Data by Decedent Race Max N=53				
	Complete (N)	Missing/Don't Know (N)	Completeness (%)	X^2 Test Statistic, df*	P-value**
Clinical Site-Specific Discrimination					
Obtaining COVID-19 Testing					
White	26	6	81. 3%	--	1.0
Black	15	4	78.9%		
Overall	41	10	80%		
Doctor's Office					
White	15	8	65.2%	--	0.44
Black	9	2	81.8%		
Overall	24	10	71%		
Urgent Care				--	0.60
White	2	31	6.1%		
Black	2	15	11.8%		
Overall	4	46	8%		
Emergency Room				0.27, df=1	0.61
White	15	19	44.1%		
Black	7	12	36.8%		
Overall	22	31	42%		
Hospitalization				--	0.15
White	28	4	87.5%		
Black	13	6	68.4%		
Overall	41	10	80%		
Total (All 5 Situations Together)				0.07, df=1	0.80
White	86	68	55.8%		
Black	46	39	54.1%		
Overall	132	107	55%		

*If X^2 statistic column missing, Fisher's exact test was conducted instead.
**P-value reported for the difference in completeness between White and Black decedents.

Table 5 displays the prevalence of COVID-19 testing in the sample reported by the NOK as well as NOK-reported discrimination in the sample. About two-thirds of decedents were tested for COVID-19 prior to death, with 60% receiving a positive result, 24% receiving a negative result, and 16% of NOK unsure of the results.

NOK-Reported Health Care Discrimination

Regarding perceived discrimination, 28% of NOK reported any discrimination experienced by the decedent (Table 5). Clinical setting-specific discrimination prevalence reported by the NOK varied from 2% at a doctor's office to 18% in the emergency room.

Table 5. Prevalence of COVID-19 testing and reported discrimination in the Michigan COVID-19 mortality review sample

Michigan COVID-19 Mortality Review Sample Max N=55	N	(%)
COVID-19 Testing		
Tested prior to death		
Yes	34	(68)
No	16	(32)
Test results (of those tested)		
Positive	22	(60)
Negative	9	(24)
Unsure	6	(16)
Reported Discrimination		
Any discrimination		
Yes	15	(28)
No	39	(72)
Discrimination in obtaining testing		
Yes	7	(13)
No	34	(63)
Unsure	11	(20)
Not Applicable	2	(4)

Table 5. (cont'd)

Discrimination at a doctor's office		
Yes	1	(2)
No	24	(48)
Unsure	6	(12)
Not Applicable	19	(38)
Discrimination at an urgent care		
Yes	1	(12)
No	3	(38)
Unsure	1	(12)
Not Applicable	3	(38)
Discrimination at the ER		
Yes	5	(18)
No	17	(63)
Unsure	5	(18)
Not Applicable	0	(0)
Discrimination in being hospitalized		
Yes	7	(14)
No	34	(65)
Unsure	9	(17)
Not Applicable	2	(4)

Missing Data: Tested prior to death (N=5); Test results (N=18); Any discrimination (N=1); Discrimination in obtaining testing (N=1); Discrimination at a doctor's office (N=5); Discrimination at an urgent care (N=47); Discrimination at the ER (N=28); Discrimination in being hospitalized (N=3)

Table 6 displays the prevalence of reported discrimination in the sample by sociodemographic attributes of both the decedent and NOK. When examining this distribution by race/ethnicity, we see that NOK of non-Hispanic Black decedents were almost three times as likely to report perceived discrimination as NOK of non-Hispanic White decedents (OR: 2.7, 95% CI: [0.8, 9.3]). NOK of decedents from the out tri-county region were most likely to report discrimination (32%), followed by all other counties (25%), and city of Detroit (13%). However, the association between region and discrimination was not significant (p=0.51). NOK who were children or siblings of the decedent were the most likely to report discrimination (38%), followed by extended family members (12%), and spouse or parent (11%). However, this association was not significant (p=0.23).

Table 6. Prevalence of reported discrimination by sociodemographic attributes of the decedent and next of kin.

	Discrimination Reported Max N= 54				
	Yes N (%)	**No** N (%)	**X^2 Statistic, df***	**P-value****	**Odds Ratio [95% CI]**
Decedent Characteristics					
Race/ethnicity			2.56, df=1	0.11	2.7 [0.8, 9.3]
Non-Hispanic White (ref)	7 (21)	26 (79)			
Non-Hispanic Black	8 (42)	11 (58)			
Gender			0.73, df=1	0.39	1.7 [0.5, 6.0]
Male	10 (32)	21 (68)			
Female (ref)	5 (22)	18 (78)			
Region			--	0.51	
Detroit (ref)	1 (13)	7 (87)			
Out Tri-County	11 (32)	23 (68)			3.3 [0.4, 30.1]
Other County	3 (25)	9 (75)			2.3 [0.2, 27.6]
Next of Kin Characteristics					
Gender			--	0.69	0.91 [0.2, 3.5]
Male	4 (29)	10 (71)			

Table 6. (cont'd)

Female (ref)	11 (31)	25 (69)			
NOK relationship to decedent			--	0.23	
Spouse or parent (ref)	1 (11)	8 (89)			
Child or sibling	13 (38)	21 (62)			4.9 [0.6, 44.3]
Extended family	1 (12)	7 (88)			1.1 [0.1, 21.9]
Non-family member	0 (0)	3 (100)			-- [a]

Missing Data: Race/ethnicity (N=3); Decedent gender (N=1); Region (N=1); NOK gender (N=4); NOK relationship to decedent (N=1)

* If X^2 statistic column missing, Fisher's exact test was conducted instead.

**P-value reported for a Chi-square test of independence.

[a] Noncalculable

Tables 7 and 8 display the qualitative data from next of kin interviews regarding the perceived discrimination questions. These answers were given in response to the following question(s): *Do you think [the deceased] was treated differently from others or experienced discrimination in trying to or obtaining COVID-19 testing, receiving treatment for COVID-19 at an emergency room, or in being hospitalized for COVID-19? For example, was [the deceased] denied care or was care delayed or inadequate?*

Seven quotations of the 15 provided were chosen that highlight the different types of discrimination perceived by the NOK (Table 7). The most commonly reported types were comorbidity/preexisting conditions (27%) and age discrimination (20%) (Table 8). Drug use and racial discrimination were rare in the sample, with only one occurrence of each being reported (7%).

Table 7. Quotes from next of kin in response to perceived discrimination questions

NOK Reporting Discrimination N=15
1. "I think they [hospital staff] looked at her and her age and, you know, they didn't do what they would've done with someone that was younger.."
2. "They [ER] didn't give her [decedent] a test. I think they discriminated against her because of her age."
3. "Actually, yeah. He was an older guy with preexisting conditions. And with all the press and the media about COVID, the hospitals are going to be overwhelmed, everybody's going to be on the media—going down everybody's throats, everybody's in a panic, do you think they're going to treat the old guy with CHF and COVID? Or are they going to send him to a floor and let him die? . . . I don't think they did their due diligence in treating him. I think they were afraid they were going to be overwhelmed, so they let the old guy die."

Table 7. (cont'd)

4. "Yes. Being that he had no guardian, and he was unable to communicate with dementia, he had no voice. He couldn't express to them [ER staff] his true feelings of what was going on because he had dementia. Was he getting the care he was supposed to get, did it get worse because he was there, what else did he get exposed to while he was there? . . . He had no voice, no way to communicate, so I know he was mistreated."

5. "Because, like I said, she did do drugs, and when she came in [to ER], they could've said 'Well, she's a drug addict.'" When asked the question, "Do you think she was treated differently because of her drug history?", NOK said, "I think so."

6. "Well, sure, in a way because they were trying to save the ones that mostly didn't have underlying health issues. The doctor when he [decedent] first got there called me and said 'Well, he [decedent] has got a lot going on for himself. Do you want to put him on a ventilator?' . . . They were trying to make sure that they put ventilators on the ones that didn't have other health issues."

7. "I felt like she was being discriminated against because of her illness. They [hospital staff] just felt that whoever didn't have a quality of life or wasn't going to live, we're just going to let them pass away. I felt like it was racially motivated to a certain degree."

Table 8. Prevalence of discrimination types reported by NOK

NOK Reporting Discrimination N=15	N	%
Reason for Reporting Discrimination		
Age	3	20%
Comorbidities/preexisting conditions	4	27%
Drug use	1	7%
Race	1	7%
Denied/delayed COVID-19 testing	2	13%
Inadequate care, reason not specified	4	27%

DISCUSSION

This study provides insights regarding proxy-reported health care discrimination experienced by those that passed away from COVID-19 in the state of Michigan in the early phase of the pandemic. Additionally, we have provided an evaluation of the MiCOVDI next of kin interview process, examining the completeness of the data collected.

The prevalence of proxy-reported health care discrimination in our study population was 28%. This is close to the estimate obtained in a U.S. survey, which concluded 20% of adults have experienced health care discrimination.[14] Regarding clinical site-specific discrimination, obtaining COVID-19 testing, being hospitalized, and visiting an emergency room were the most likely situations for discrimination to be reported by the NOK.

Upon further examination of the NOK quotes regarding discrimination, we can see that delayed testing was an important reason given by proxies for answering "yes" to those questions. Unfortunately, COVID-19 testing shortages were a common issue early in the pandemic, with some research suggesting as many as 50% of people experiencing COVID-19 symptoms did not receive a test.[18] Another contributing factor to perceived discrimination was the inability of family members to physically be with the decedents in the hospital. As can be seen by quote 4 (Table 7) this proved to be a significant issue for family members of those with impaired cognitive function, such as dementia. While limiting and/or banning visitors helps reduce COVID-19 spread, some argue that guardians of those with dementia should be considered essential and permitted to be physically present when undergoing COVID treatment.[38] Allowing caregivers to be present ensures that the needs of patients with dementia will be properly advocated for.[38] Lastly, age, drug history, race, and comorbidity discrimination were cited as reasons for perceived discrimination. Many NOK felt that resources were being withheld from

those with underlying health issues (quotes 1, 3, 6-7) (Table 7). Some felt that their family members were "allowed to pass" due to their comorbidities and perhaps their race/ethnicity as well (quote 7) (Table 7).

When examining proxy-reported discrimination by attributes of the decedent and NOK, we found no significant associations. This is likely due to our small sample size, as some associations were large in magnitude and approached significance (race/ethnicity of the decedent and NOK relationship to decedent). Given that racial/ethnic discrimination is one of the most common types of health care discrimination[14], it is not surprising that NOK of Black decedents were almost three times as likely to report discrimination as NOK of White decedents (OR=2.7). Regarding the NOK's relationship to the decedent, children or siblings were more than three times as likely to report discrimination as spouses or parents (38% vs. 11%, respectively). This is consistent with current literature, which finds that children tend to report worse health care experiences, and spouses tend to report more positive experiences.[32,34]

The sampling scheme for the MiCOVDI project (Figure 2) was intended to create a sample representative of the COVID-19 deaths during the first wave of the pandemic. Because MiCOVDI aimed to detect racial disparities in health care, deaths from Detroit were oversampled in hopes of having sufficient racial variability in the sample to detect differences between groups. However, due to a low response rate (29%), only eight out of 55 NOK interviews were conducted from Detroit. Decedents from this location remain underrepresented in our sample. This may explain the race/ethnicity distribution in the study sample. About two-thirds of decedents in the sample were White, which is surprising given that those of non-Hispanic Black race/ethnicity are about twice as likely to die from COVID-19 as those that are non-Hispanic White.[39] From March – October, 2020 in Michigan, 58% of COVID-19 deaths

were among White individuals and 39% were among Black individuals.[40] While White individuals had a higher number of absolute deaths, the mortality rate was over three times higher for Black individuals (4.3 vs 15.6 per 10,000).[40] Almost 80% of Detroit's population is comprised of people of Black or African American race/ethnicity.[41] Thus, our low response rate in this region prohibited us from capturing a significant portion of Black decedents, and our results are likely not generalizable to the city of Detroit. If the participants from Detroit (i.e., the nonrespondents) differed significantly in their health care experiences from those in the study that responded, it may have impacted our ability to accurately report the perceived discrimination prevalence.

Upon further examination of sociodemographic and health-related characteristics of the sample (n=55), we can conclude the majority were at high risk for COVID-19 mortality. The majority of the sample (76%) was over the age of 65 at time of death, indicating increased risk for COVID-19 mortality.[5] MiCOVDI captured no deaths under age 35 years, and 24% of deaths in the sample were 35-64 years of age. This is similar to the age distribution of COVID-19 deaths in Michigan during 2020: <35 years (0.6%), 35-64 years (16%), 65+ years (83%).[42] The sex distribution in the MiCOVDI sample (56% male, 44% female) is almost identical to that of COVID-19 deaths in Michigan during 2020 (54% male, 46% female).[43] The median annual income in the study population was $21,600, which falls far below Michigan's median income in 2020 of $59,234.[44] However, this is not surprising given that the majority of the sample is either retired (64%) or in a nursing home (20%). Additionally, it is known that low income is associated with increased risk of COVID-19 mortality.[15] Lastly, the prevalence of comorbidities in the sample was high, with 90% of decedents having at least one comorbidity. This is to be expected, as comorbidities are a known risk factor for COVID-19 mortality.[5] Apart from the

race/ethnicity distribution, the COVID-19 mortality risk factor profile of the sample is consistent with current knowledge.

In our assessment of the completeness of the survey responses, we report several findings. First, the MiCOVDI project attained a response rate of 55% for NOK interviews. This is higher than the response rates (< 40%) of two other studies utilizing NOK interviews to study COVID-19 mortality.[24,25] However, the response rate did differ by geographical region, with the city of Detroit having the lowest response rate (29%), followed by all other counties (50%), and the tri-county region (73%).

Regarding the completeness of the survey responses, estimates varied depending on the interview section examined. Overall, the average completeness was 59%. With regards to our outcome of interest, perceived discrimination, the completion was 98% when assessed dichotomously (any vs. none) and fell to 54% when examined as clinical site-specific discrimination. A common theme appears to be that participants are more likely to provide a response when the question calls for a dichotomous answer, rather than a more complex one. For example, the completeness percentage for whether or not the decedent visited certain locations prior to their death was 95%. When asked how many times the decedent visited said locations (i.e., requiring a more detailed or complex answer), this fell to 10%. When asked whether or not the decedent was symptomatic prior to death, the completion was 93%. Again, this fell to 51% when asked to elaborate on specific symptoms experienced. Phrasing questions in ways that can be answered with a yes/no response when possible may be an effective way to decrease the number of missing data in NOK interviews. Additionally, focusing on high-level concepts as opposed to specific details may reduce the missingness of data in interviews.

This thesis has several limitations. First, age was not available in the NOK interview data. The age distribution of decedent age was provided by collaborators from death certificate data. Thus, NOK interview variables (i.e., discrimination, comorbidities) could not be examined within the context of decedent age. Second, this thesis relies entirely on proxy responses. The validity of proxy responses has been shown to vary with the interview content, relationship of proxy to the patient, and the proxy's involvement in the patient's medical care.[30–34] However, given that this thesis examines the experiences of those who died from COVID-19, we have no feasible way to gather that information firsthand. Even if we were to have recruited participants and NOK from a hospitalized population of COVID-19 patients, it would likely have been very difficult to interview hospitalized participants. Sample size is another limiting factor of our study. One of our targeted geographic locations, Detroit, is underrepresented in our sample, and our overall sample size is relatively small (n=55). Ideally, future projects on this topic will conduct more interviews and be able to detect significant relationships between proxy-reported discrimination and decedent attributes such as race, gender, and region of location, if they exist. The wording of the discrimination questions themselves suffer from lack of specificity. Since distinct types of discrimination were not explicitly asked about, we were limited in our analysis of proxies' reasoning for reporting discrimination. Lastly, cause of death for this thesis relied entirely on death certificates, which may be subject to human error and misclassification.[45] However, the Centers for Disease Control and Prevention examined death certificate data related to COVID-19 in 2020 and reported a high accuracy.[46] The authors discovered that 95% deaths attributed to COVID-19 and other causes followed a biologically plausible chain of events that occur in COVID-19 disease (i.e., respiratory failure and COVID-19).[46] While we cannot rule out misclassification of COVID-19 status in our study population, obtaining data from death

certificates is a feasible and standardized way to identify eligible participants. It is important to note that research has shown a significant number of excess deaths during 2020 – 2021, even after accounting for confirmed COVID-19 deaths.[47] There may be a significant proportion of COVID-19 deaths that were misclassified as non-COVID deaths, thus reducing our ability to capture a sample representative of all COVID-19 deaths.[47]

This study also has several strengths. We analyzed data from the MiCOVDI project, and to our current knowledge, it is the only one of its kind in that it aims to investigate discrimination experienced by those that passed away from COVID-19. We were able to gain insight not only into what decedents may have experienced prior to death from COVID-19, but how their family members perceived this experience with the health care system. The comprehensive interview allowed for an extensive dataset, covering sociodemographic and health-related information on the decedent. In addition to analyzing the interview responses, we were able to assess the completeness of the survey responses. This allowed us to determine which sections of the interview were most complete, and which types of questions were susceptible to missing data. While NOK interviews are subject to limitations with their validity and reliability, they are an important tool in death investigations that can have a significant public health impact.

CONCLUSION

This study showed that NOK-reported health care discrimination during the first wave of the pandemic did occur. Proxies perceived the decedent experienced discrimination due to age, comorbidity, race, and drug use history in obtaining COVID-19 testing and treatment prior to death. Perceived discrimination was most likely to be reported in obtaining testing, being hospitalized, or at an emergency room. These results provide information on the family's experience during the difficult time of losing a loved one during the early days of the COVID-19 pandemic. Better understanding their perception of the situation may help inform interventions that aim to improve health care equity. There remains a need for research that focuses on proxy-reported discrimination as it relates to COVID-19 mortality. Future endeavors may focus on increasing sample size, assessing if/how proxy reports of health care discrimination changed throughout the course of the pandemic, and improving the specificity of interview questions to reduce ambiguity. Additionally, one could propose an alternative study design of interviewing COVID-19 survivors to obtain firsthand reports of discrimination, thus eliminating the limitations seen with proxy-reported data.

APPENDIX

Table A1. NOK interview questions and their responses

Interview Question	Original Response	Transformed Response
Relationship to the [deceased]	Open-ended	1: Spouse or parent 2: Child or sibling 3: Extended family 4: Non-family member
Can you tell me about what happened to [the deceased]?	Open-ended	
How was [the deceased's] death explained to you?	Open-ended	
Has [deceased] seen/met others at church/temple in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others at church/temple in the 14 days before their death?	# of times 99: Don't know	
Has [deceased] seen/met with neighbors in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met with neighbors in the 14 days before their death?	# of times 99: Don't know	
Has [deceased] seen/met others at the park in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others at the park in the 14 days before their death?	# of times 99: Don't know	
Has [deceased] seen/met others at a restaurant in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others at a restaurant in the 14 days before their death?	# of times 99: Don't know	
Has [deceased] seen/met others at stores, including grocery stores, in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others at stores in the 14 days before their death?	# of times 99: Don't know	

Table A1. (cont'd)

Has [deceased] seen/met others at a workplace in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others at a workplace in the 14 days before their death?	# of times 99: Don't know	
Has [deceased] seen/met others anywhere else in the 14 days before their death?	1: Yes 2: No 3: Don't know	
If yes, how many times has [the deceased] met others anywhere else in the 14 days before their death?	# of times 99: Don't know	
Did [the deceased] have any symptoms in the 14 days before being hospitalized or dying?	1: Yes 2: No 3: Don't know	
Did they have fever or chills?	1: Yes 2: No 3: Don't know	
Cough?	1: Yes 2: No 3: Don't know	
Shortness of breath or difficulty breathing?	1: Yes 2: No 3: Don't know	
Fatigue?	1: Yes 2: No 3: Don't know	
Muscle or body aches?	1: Yes 2: No 3: Don't know	
Headache?	1: Yes 2: No 3: Don't know	
New loss of taste or smell?	1: Yes 2: No 3: Don't know	
Sore throat?	1: Yes 2: No 3: Don't know	

Table A1. (cont'd)

Congestion or runny nose?	1: Yes 2: No 3: Don't know	
Nausea or vomiting?	1: Yes 2: No 3: Don't know	
Diarrhea?	1: Yes 2: No 3: Don't know	
Was [the deceased] tested for COVID-19 before he/she was hospitalized/died?	1: Yes 2: No	
Where did [the deceased) get his/her first COVID-19 test?	Open-ended	
What were the results?	1: Positive 2: Negative 3: Don't know	
Were there any other COVID-19 tests done before [the deceased] was hospitalized/died?	1: Yes 2: No	
Where did [the deceased] get his/her next COVID-19 test?	Open-ended	
What were the results?	1: Positive 2: Negative 3: Don't know	
When doctors were explaining the results of the COVID-19 test(s), did you or [the deceased] understand everything they were saying, meaning was it clear or did it seem like they were using medical jargon?	Open-ended	
Can you describe your first impression of the health provider that gave the COVID-19 test? Were they willing to help, stressed, rushed, eager to give your family member the information he/she needed? Or something other than what I listed?	Open-ended	

Table A1. (cont'd)

Do you think [the deceased] was treated differently from others or experienced discrimination in trying to or obtaining COVID-19 testing? For example, was testing denied or was delayed at any point you know about.	Open-ended	1: Yes 2: No 3: Don't Know . : Missing
Tell me about any medical care that [the deceased] tried to or did obtain in the 30 days before they were hospitalized or died from COVID-19. Please tell me about all the kinds of care, including calling a doctor's office or going to an emergency room, even if [the deceased] was not seen. We also want to know why they sought medical care? Were they having particular symptoms or concerns? We want to understand all of what happened between the deceased falling ill and their death. For example, I want to know about [the deceased] going to the emergency room even if he/she was sent home initially. I want to know if they were admitted to a hospital and then discharged before they died. Were they in a long term facility at some point before dying?	Open-ended	
Did [the deceased] have a chest x-ray in the 14 days before their death?	0: No 1: Yes 9: Don't know	

Table A1. (cont'd)

When was the last time [the deceased] had a chest x-ray?	mm/dd/yyyy	
Where was the chest x-ray done?	Open-ended	
Did [the deceased] have a chest CT in the 14 days before their death?	0: No 1: Yes 9: Don't know	
When was the last time [the deceased] had a chest CT?	mm/dd/yyyy	
Where was the chest CT done?	Open-ended	
Was [the deceased] given antibiotics in the week before their death?	0: No 1: Yes 9: Don't know	
What was [the deceased's] height in feet?	Open-ended 9: Don't know	
What was [the deceased's] height in inches?	Open-ended 9: Don't know	
What was [the deceased's] weight?	Open-ended 999: Don't know	
Where did [the deceased] die?	1: Emergency room 2: Intensive care 3: Another part of the hospital 4: Nursing home 5: Prison 6: Ambulance 7: Home 8: Work 9: Some other location 99: Don't know	
If they died in the hospital: How long after [the deceased] went to the hospital did he/she die (hours)?	Open-ended	
If they died in the hospital: How long after [the deceased] went to the hospital did he/she die (days)?	Open-ended	
If they died in the hospital: How long after [the deceased] went to the hospital did he/she die (weeks)?	Open-ended	

Table A1. (cont'd)

If they died in the hospital: How long after [the deceased] went to the hospital did he/she die (months)?	Open-ended	
If [the deceased] did not die in an ambulance or at the hospital: Was CPR performed?	0: No 1: Yes 9: Don't know	
Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at a doctor's office? For example, was [the deceased] denied care or was care delayed or inadequate?	Open-ended	1: Yes 2: No 3: Don't Know . : Missing
Were you or [the deceased] able to ask all the questions you or they wanted to and in the way you or they wanted to at the doctor's office, or did it feel rushed?	Open-ended	
You may have already said this, but can you tell me if [the deceased] had gone to an Urgent Care in the 14 days before he/she was hospitalized or died?	0: No 1: Yes 9: Don't know	
Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at urgent care? For example, was [the deceased] denied care or was care delayed or inadequate?	Open-ended	1: Yes 2: No 3: Don't Know . : Missing
You may have already told me, but can you tell me if [the deceased] had gone to any Emergency Room in the 14 days before he/she was hospitalized or died?	0: No 1: Yes 9: Don't know	

Table A1. (cont'd)

Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at emergency room care? For example, was [the deceased] denied care or was care delayed or inadequate?	Open-ended	1: Yes 2: No 3: Don't Know . : Missing
Do you think [the deceased] was treated differently from others or experienced discrimination in being hospitalized for COVID-19? For example, was [the deceased] denied care or was care delayed or inadequate?	Open-ended	1: Yes 2: No 3: Don't Know . : Missing
If [the deceased] did not have medical care in the 14 days before he/she died or went to the hospital, tell me why you think that was the case. *Mark all that apply.*	1: Lack of health insurance 2: Cost 3: Wait was too long 4: Transportation 5: Miss work 6: Didn't like doctors 7: Didn't think symptoms were that bad 8: Didn't have a primary care doctor 9: Couldn't get an appointment 10: Other 99: Don't know	
How often did [the deceased] go to the doctor/clinic in the last year before they died?	# of times	
Did [the deceased] have health insurance?	0: No 1: Yes 9: Don't know	
Did the health insurance cover outpatient care?	0: No 1: Yes 9: Don't know	
What type of insurance. *Be very specific!*	Open-ended	

Table A1. (cont'd)

How much did [the deceased] have to pay per visit?	Open-ended	
When was [the deceased's] last visit to the doctor before he/she was hospitalized/died?	mm/dd/yyyy	
Prior to the final hospitalization when [the deceased] died, when was his/her last hospitalization?	mm/dd/yyyy	
Did [the deceased] have a flu shot this past fall/winter?	0: No 1: Yes 9: Don't know	
Had [the deceased] ever have a pneumonia shot?	0: No 1: Yes 9: Don't know	
If yes, how many times did he/she get a pneumonia shot?	# of times 99: Don't know	
I'm going to ask you about the health of [the deceased], such as history of chronic disease.. Did [the deceased] have diabetes?	0: No 1: Yes 9: Don't know	
High blood sugar?	0: No 1: Yes 9: Don't know	
High cholesterol?	0: No 1: Yes 9: Don't know	
Heart disease?	0: No 1: Yes 9: Don't know	
Dementia?	0: No 1: Yes 9: Don't know	
Cancer?	0: No 1: Yes 9: Don't know	
Kidney disease?	0: No 1: Yes 9: Don't know	
Asthma?	0: No 1: Yes 9: Don't know	

Table A1. (cont'd)

COPD/Emphysema?	0: No 1: Yes 9: Don't know	
Other lung condition?	0: No 1: Yes 9: Don't know	
Lupus or some other connective tissue disease?	0: No 1: Yes 9: Don't know	
Did [the deceased] use products from health food stores/home remedies that were not prescribed by a doctor?	0: No 1: Yes 9: Don't know	
What kind of work did [the deceased] do?	Open-ended 2: Was not working	
Was [the deceased] required to go to work during the Governor's stay at home order?	0: No 1: Yes 9: Don't know	
Did [the deceased] work in the 14 days before his/her death?	0: No 1: Yes 9: Don't know	
What was the name and location of employer?	Open-ended	
If [the deceased] was not working, please indicate why:	1: Retired, list longest job held: 2: Nursing home/assisted living 3: Prisoner 4: Student 5: Homemaker 6: Disabled, list reason: 7: Other, list reason: 9: Don't know	
Did [the deceased] ever smoke cigarettes?	0: No 1: Yes 9: Don't know	
If Yes, how old was [the deceased] when they first started smoking cigarettes?	Open-ended 99: Don't know	

Table A1. (cont'd)

If Yes, and if he/she stopped smoking cigarettes completely, how old was [the deceased] when he/she stopped?	Open-ended 99: Don't know	
If Yes, on the average of the entire time they smoked, how many cigarettes did he/she smoke per day?	Open-ended 99: Don't know	
Did [the deceased] ever smoke cigars, including Black and Milds?	0: No 1: Yes 9: Don't know	
If Yes, how old was [the deceased] when they first started smoking cigars?	Open-ended 99: Don't know	
If Yes, and if he/she stopped smoking cigars completely, how old was [the deceased] when he/she stopped?	Open-ended 99: Don't know	
If Yes, on the average of the entire time they smoked, how many cigars did he/she smoke per day?	Open-ended 99: Don't know	
Did [the deceased] ever smoke a pipe?	0: No 1: Yes 9: Don't know	
If Yes, how old was [the deceased] when they first started smoking a pipe?	Open-ended 99: Don't know	
If Yes, and if he/she stopped smoking a pipe completely, how old was [the deceased] when he/she stopped?	Open-ended 99: Don't know	
If Yes, on the average of the entire time they smoked, how many pipes did he/she smoke per day?	Open-ended 99: Don't know	
Did [the deceased] ever vape or use e-cigarettes?	0: No 1: Yes 9: Don't know	
If Yes, how old was [the deceased] when they first started vaping/using e-cigs?	Open-ended 99: Don't know	

Table A1. (cont'd)

If Yes, and if he/she stopped vaping/using e-cigs completely, how old was [the deceased] when he/she stopped?	Open-ended 99: Don't know	
If Yes, on the average of the entire time they smoked, how often did he/she vape/use e-cigs per day?	Open-ended 99: Don't know	
Was [the deceased] around other smokers…	1: At home 2: At work 3: Both at work and home 0: Neither at work nor home 9: Don't know	
Did [the deceased] use alcohol?	0: No 1: Yes 9: Don't know	
Did [the deceased] use marijuana?	0: No 1: Yes 9: Don't know	
Did [the deceased] use prescription pain relievers such as Vicodin, Percocet or Demerol?	0: No 1: Yes 9: Don't know	
Did [the deceased] use prescription antidepressants or anti-anxiety drugs, such as Prozac, Xanax or Zoloft?	0: No 1: Yes 9: Don't know	
Did [the deceased] use any drugs that weren't prescribed, including tranquilizers, cocaine, heroin, amphetamines, or hallucinogens?	0: No 1: Yes 9: Don't know	

Table A1. (cont'd)

With which racial and ethnic grouping(s) would have [the deceased] identified himself/herself: *(select all that apply)*	1: American Indian / Alaska Native 2: Latinx / Hispanic American 3: Non-Hispanic White / Euro-American 4: East Asian / Asian American 5: Middle Eastern or North African 6: Black / Afro-Caribbean / African American 7: Native Hawaiian / Other Pacific Islander 8: Another race or ethnicity not listed above	1: Non-Hispanic White 2: Non-Hispanic Black
What was the total family income for the year preceding [the deceased] death?	Open-ended	
How many people lived in the household with [the deceased]?	Open-ended	
Do you know if anyone living with [the deceased] has tested positive for COVID?	1: Yes, specify number 2: No	
Decedent's region of residence	1: Detroit 2: Out Tri-County 3: All other counties	
NOK Gender	*Not specifically asked*	Obtained from reading qualitative responses 1: Male 2: Female . : Missing
Decedent Gender	*Not specifically asked*	Obtained from reading qualitative responses 1: Male 2: Female . : Missing

Table A1. (cont'd)

Was there any discrimination perceived by the NOK?	*Not specifically asked- created by us as a composite variable of other 5 discrimination questions*	1: Yes 2: No 3: Don't Know . : Missing

Table A2. NOK interview question groupings for completeness analysis

Overall (N=120)
Any Discrimination Composite variable created from 5 clinical site-specific discrimination questions
Perceived discrimination at specific locations (i.e., urgent care, doctor's office) Do you think [the deceased] was treated differently from others or experienced discrimination in trying to or obtaining COVID-19 testing? For example, was testing denied or was delayed at any point you know about. Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at a doctor's office? For example, was [the deceased] denied care or was care delayed or inadequate? Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at urgent care? For example, was [the deceased] denied care or was care delayed or inadequate? Do you think [the deceased] was treated differently from others or experienced discrimination in receiving treatment for COVID-19 at emergency room care? For example, was [the deceased] denied care or was care delayed or inadequate? Do you think [the deceased] was treated differently from others or experienced discrimination in being hospitalized for COVID-19? For example, was [the deceased] denied care or was care delayed or inadequate?
Did the decedent visit these locations 14d prior to death (Y/N) Has [deceased] seen/met others at church/temple in the 14 days before their death? Has [deceased] seen/met with neighbors in the 14 days before their death? Has [deceased] seen/met others at the park in the 14 days before their death? Has [deceased] seen/met others at a restaurant in the 14 days before their death? Has [deceased] seen/met others at stores, including grocery stores, in the 14 days before their death? Has [deceased] seen/met others at a workplace in the 14 days before their death? Has [deceased] seen/met others anywhere else in the 14 days before their death?
# of times decedent visited each location 14d prior to death If yes, how many times has [the deceased] met others at church/temple in the 14 days before their death? If yes, how many times has [the deceased] met with neighbors in the 14 days before their death? If yes, how many times has [the deceased] met others at the park in the 14 days before their death? If yes, how many times has [the deceased] met others at a restaurant in the 14 days before their death? If yes, how many times has [the deceased] met others at stores in the 14 days before their death? If yes, how many times has [the deceased] met others at a workplace in the 14 days before their death? If yes, how many times has [the deceased] met others anywhere else in the 14 days before their death?
Symptomatic prior to death (Y/N) Did [the deceased] have any symptoms in the 14 days before being hospitalized or dying?
Specific symptoms experienced Did they have fever or chills? Cough? Shortness of breath or difficulty breathing?

Table A2. (cont'd)

Fatigue?
Muscle or body aches?
Headache?
New loss of taste or smell?
Sore throat?
Congestion or runny nose?
Nausea or vomiting?
Diarrhea?

COVID-19 testing
Was [the deceased] tested for COVID-19 before he/she was hospitalized/died?
Where did [the deceased) get his/her **first** COVID-19 test?
What were the results?
Were there any other COVID-19 tests done before [the deceased] was hospitalized/died?
Where did [the deceased] get his/her next COVID-19 test?
What were the results?

Medical care received before death
You may have already told me, but can you tell me if [the deceased] had gone to any Emergency Room in the 14 days before he/she was hospitalized or died?
You may have already said this, but can you tell me if [the deceased] had gone to an Urgent Care in the 14 days before he/she was hospitalized or died?
Did [the deceased] have a chest x-ray in the 14 days before their death?
Did [the deceased] have a chest CT in the 14 days before their death?
Was [the deceased] given antibiotics in the week before their death?
If [the deceased] did not die in an ambulance or at the hospital:
Was CPR performed?
If [the deceased] did not have medical care in the 14 days before he/she died or went to the hospital, tell me why you think that was the case. *Mark all that apply.*

NOK descriptions of health care experience
Can you tell me about what happened to [the deceased]?
How was [the deceased's] death explained to you?
When doctors were explaining the results of the COVID-19 test(s), did you or [the deceased] understand everything they were saying, meaning was it clear or did it seem like they were using medical jargon?
Can you describe your first impression of the health provider that gave the COVID-19 test? Were they willing to help, stressed, rushed, eager to give your family member the information he/she needed? Or something other than what I listed?
Tell me about any medical care that [the deceased] tried to or did obtain in the 30 days before they were hospitalized or died from COVID-19.

Please tell me about all the kinds of care, including calling a doctor's office or going to an emergency room, even if [the deceased] was not seen. We also want to know why they sought medical care? Were they having particular symptoms or concerns?

We want to understand all of what happened between the deceased falling ill and their death. For example, I want to know about [the deceased] going to the emergency room even if he/she was sent

Table A2. (cont'd)

home initially. I want to know if they were admitted to a hospital and then discharged before they died. Were they in a long term facility at some point before dying?

Were you or [the deceased] able to ask all the questions you or they wanted to and in the way you or they wanted to at the doctor's office, or did it feel rushed?

Past medical care
When was the last time [the deceased] had a chest x-ray?
Where was the chest x-ray done?
When was the last time [the deceased] had a chest CT?
Where was the chest CT done?
How often did [the deceased] go to the doctor/clinic in the last year before they died?
When was [the deceased's] last visit to the doctor before he/she was hospitalized/died?
Prior to the final hospitalization when [the deceased] died, when was his/her last hospitalization?
Did [the deceased] have a flu shot this past fall/winter?
Had [the deceased] ever have a pneumonia shot?
If yes, how many times did he/she get a pneumonia shot?

Height and weight of decedent
What was [the deceased's] height in feet?
What was [the deceased's] height in inches?
What was [the deceased's] weight?

Place of death
Where did [the deceased] die?

Timing of death relative to hospital arrival
How long after [the deceased] went to the hospital did he/she die (hours)?
How long after [the deceased] went to the hospital did he/she die (days)?
How long after [the deceased] went to the hospital did he/she die (weeks)?
How long after [the deceased] went to the hospital did he/she die (months)?

Insurance coverage
Did [the deceased] have health insurance?
Did the health insurance cover outpatient care?
What type of insurance. *Be very specific!*
How much did [the deceased] have to pay per visit?

Comorbidities
I'm going to ask you about the health of [the deceased], such as history of chronic disease.. Did [the deceased] have diabetes?
High blood sugar?
High cholesterol?
Heart disease?
Dementia?
Cancer?
Kidney disease?
Asthma?
COPD/Emphysema?

Table A2. (cont'd)

Other lung condition?
Lupus or some other connective tissue disease?

Employment of decedent
What kind of work did [the deceased] do?
Was [the deceased] required to go to work during the Governor's stay at home order?
Did [the deceased] work in the 14 days before his/her death?
What was the name and location of employer?
If [the deceased] was not working, please indicate why:

Drug use (Y/N)
Did [the deceased] ever smoke cigarettes?
Did [the deceased] ever smoke cigars, including Black and Milds?
Did [the deceased] ever smoke a pipe?
Did [the deceased] ever vape or use e-cigarettes?
Did [the deceased] use alcohol?
Did [the deceased] use marijuana?
Did [the deceased] use prescription pain relievers such as Vicodin, Percocet or Demerol?
Did [the deceased] use prescription antidepressants or anti-anxiety drugs, such as Prozac, Xanax or Zoloft?
Did [the deceased] use any drugs that weren't prescribed, including tranquilizers, cocaine, heroin, amphetamines, or hallucinogens?
Did [the deceased] use products from health food stores/home remedies that were not prescribed by a doctor?

Drug use specifics
If Yes, how old was [the deceased] when they first started smoking cigarettes?
If Yes, and if he/she stopped smoking cigarettes completely, how old was [the deceased] when he/she stopped?
If Yes, on the average of the entire time they smoked, how many cigarettes did he/she smoke per day?
If Yes, how old was [the deceased] when they first started smoking cigars?
If Yes, and if he/she stopped smoking cigars completely, how old was [the deceased] when he/she stopped?
If Yes, on the average of the entire time they smoked, how many cigars did he/she smoke per day?
If Yes, how old was [the deceased] when they first started smoking a pipe?
If Yes, and if he/she stopped smoking a pipe completely, how old was [the deceased] when he/she stopped?
If Yes, on the average of the entire time they smoked, how many pipes did he/she smoke per day?
If Yes, how old was [the deceased] when they first started vaping/using e-cigs?
If Yes, and if he/she stopped vaping/using e-cigs completely, how old was [the deceased] when he/she stopped?
If Yes, on the average of the entire time they smoked, how often did he/she vape/use e-cigs per day?

Race/ethnicity
With which racial and ethnic grouping(s) would have [the deceased] identified himself/herself:
(select all that apply)

Yearly income of decedent
What was the total family income for the year preceding [the deceased] death?

Table A2. (cont'd)

 # people in decedent's household
How many people lived in the household with [the deceased]?

COVID-19 status of those that lived with decedent
Do you know if anyone living with [the deceased] has tested positive for COVID?

Decedent's region of residence
Present upon receipt of dataset

Decedent's gender
Determined by reading qualitative responses

NOK's gender
Determined by reading qualitative responses

NOK relationship to decedent
Relationship to the [deceased]

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