

Determinants of Racial Misclassification in COVID-19 Mortality Data: The Role of Funeral Directors and Social Context

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Racial misclassification of American Indian and Alaska Native people has been a longstanding crisis in public health, limiting the quality of data available across Indian country. On death certificates in particular, racial misclassification can entirely hide fatal health disparities.¹ Time-consuming data linkages are often required to correct for more realistic estimates, well after the data is collected. This problem has been particularly troubling during the COVID-19 pandemic, as rapid provisional death counts based on death certificates are used to identify outbreaks and allocate resources.²

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Racial misclassification of American Indian and Alaska Native people on death certificates is widespread, and has improved little at the national level since it was first measured in 1979.³ In the most recent report by the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC), nearly 45 percent of people who identified as American Indian or Alaska Native on the Current Population Survey were misclassified as white alone after death, with another 4 percent misclassified as black alone.⁴ In addition, tribal affiliations are seldom documented, even when American Indian or Alaska Native race is recorded. American Indians or Alaska Natives are more likely to be misclassified if they die in an urban area, in the eastern half of the country, or in an area with a low co-ethnic concentration of American Indian and Alaska Native people.⁵ According to the 2010 Census, more than 70 percent of American Indian and Alaska Native people live in urban settings, so high rates of racial misclassification in these areas is particularly concerning.⁶

Due to these established patterns, urban Indian organizations are often challenged to plan health care and public health initiatives without adequate data about the deaths occurring in their own communities. As the only national membership organization representing the needs of these urban Indians, the National Council of Urban Indian Health (NCUIH) began a project in 2018 to identify ways of preventing racial misclassification of urban American Indian and Alaska Native people on their death certificates. After an information-gathering phase was completed, the COVID-19 pandemic began.

In response, this paper draws from qualitative and quantitative analyses performed during 2019 and discusses these results within the context of the 2020 pandemic. This paper answers two central questions: (1) What determinants of American Indian and Alaska Native racial misclassification emerge from practices of funeral directors and policies structuring their work; and (2) what can be inferred about COVID-19 mortality data quality based on these analyses and events during the pandemic?

BACKGROUND

The Role of Funeral Directors in Death Certification

In general, death certificates represent data from three main sources: (1) a certifying physician completes a medical history, cause of death (COD), and underlying cause(s) of death (UCOD); (2) a medical examiner or coroner performs and documents any autopsy, toxicology, or medico-legal investigation if needed; and (3) a funeral director completes demographic information about the decedent, registers the death with the state, and provides the family with a certified death certificate.⁷ The state registrar's office then performs quality control, monitors and publishes state-level data, and reports data to the CDC. National Center on Health Statistics provides a standard death certificate form for state vital registry offices to adopt, as well as instructional handbooks for funeral directors, certifying physicians, medical examiners, and coroners.⁸ The US standard death registration form follows mandated method of the Office of Management and Budget (OMB), asking one question about "Race" and a second, separate question about "Hispanic Origin."⁹ Multiple races can be selected on

this form and “Name of the enrolled or principal tribe” can be submitted if American Indian or Alaska Native is selected. Specifically, “American Indian and Alaska Native race” describes a “person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.”¹⁰

Prior research has shown that the American Indian and Alaska Native category can be interpreted differently between families and funeral directors.¹¹ Each data collector can also choose *how* they collect racial data within each jurisdiction’s unique policy environment.¹² Policies related to final dispensation can vary based on state, county, and city level regulations. Funeral director licensing varies by states, with different types of governing bodies and requirements for continuing education.¹³

We were unaware of any work linking policies with the behaviors and practices of funeral directors, or any activities specifically designed to prevent American Indian and Alaska Native misclassification before it occurs. Towards this end, NCUIH began gathering information in 2019 to better understand the role, experiences, and training of funeral directors. Though not intended as research to be generalized across the entire US funeral industry, this work was conducted to better understand our market for future training materials and communications, assess the level of their awareness on this topic, and inform future policy analysis and recommendations. NCUIH implemented both quantitative and qualitative methods, including the survey and interviews described in this report. This mixed-method approach allowed us to identify basic characteristics of our audience while gaining some depth of commentary on practices, opinions, and experiences in the field.

Based on discussions with tribal leaders and subject matter experts (SMEs), NCUIH developed a series of nested questions that are addressed in this report, including:

- ♦ How do funeral directors describe their role in collecting racial data?
- ♦ What practices do funeral directors use to classify race?
- ♦ What policies and trainings structure this work?
- ♦ Do interactions with families, demands of the job, or reporting mechanisms change the process of classification or reporting to the state?
- ♦ Have funeral directors themselves identified anything that impedes or facilitates racial classification, or would expand their capacity to implement improvements?

Death Certification during the COVID-19 Pandemic

After initial analysis were completed, the COVID-19 pandemic began. Although the same funeral director determinants continue to exist, this rapidly changed the social context in which death certificates are created and used for public health data. Families are planning funerals under drastically different conditions than before, and health professionals are rapidly reporting data from death certificates in a politically charged environment.

The largest change that funeral directors face is the transition to front line workers and “last responders.” Each funeral director has played a role in pandemic response and control, beyond their usual roles in final disposition and data collection. Funeral

directors have rapidly undertaken infection control measures, changed their business operations, trained staff, and invested in personal protective equipment (PPE) for their staff and visitors.¹⁴ Funeral directors are preventing outbreaks—both by properly handling COVID-19 decedents and promoting safe physical distancing measures during all arrangements and funerals.

Some funeral directors have also been coping as emergency responders, either by choice or by virtue of being in a COVID-19 hot spot. For example, the New York Department of Health and Mental Hygiene created a list of volunteer funeral directors as early as March 2020 who were willing to fly themselves from low-risk parts of the country and help process a large influx of deaths. State and national business associations coordinated subsequent efforts to recruit and triage these volunteers—emphasizing their essential role as “last responders.”¹⁵ New York City funeral directors faced immense caseloads, backlogs, rapidly changing policies, and personal risk due to lack of PPE access.¹⁶ As funeral directors work overtime to serve the dead and their families, it remains to be seen how the data collection aspect of their job will adapt. By reflecting on some data collection choices heading into the pandemic, this report will discuss possible effects that logistical pressures may have on American Indian and Alaska Native data quality.

The second most prominent change relates to cause of death (COD) misclassification, which has emerged as a data quality concern alongside racial misclassification. By April, the CDC’s NCHS had provided a final guidance for certifiers on how to consider COVID-19 as a COD, or underlying cause of death (UCOD).¹⁷ This provided guidelines on how to treat deaths due to suspected COVID-19 illnesses in the absence of testing confirmation. Additionally, the guidance addressed how to record a death of someone with a positive SARS-CoV2 test whose UCOD was likely unrelated (for example, a homicide or substance use overdose).

However, because the novel coronavirus has no precedent and can present with diverse symptoms, medical certifiers have been rapidly adapting ways to identify and categorize these deaths. COD misclassification can complicate whether a death is included as a provisional death count due to COVID-19, or a death due to any other cause. Therefore, American Indian and Alaska Native mortality statistics now face two possible threats to quality: COVID-19 deaths may not be recorded as American Indian or Alaska Native, and American Indian and Alaska Native deaths may not be attributed to COVID-19. It is not known whether the two errors are linked or occur independently. This paper discusses these threats to the accuracy of mortality statistics and possible implications for data quality.

Lastly, it is crucial to recognize that although racial data is always collected within a social context, the pandemic coincided with a new mainstream consciousness around race. In preparation for this report, project partners—including two Native funeral directors—were contacted to ask whether any emerging topics in the field should be covered in this report. Both immediately focused on the racial climate in the United States following the murder of George Floyd, subsequent protests against police brutality, and the armed government response to these protests. Although we have no data on how this will influence behaviors or data quality, it is likely that longstanding

issues regarding race and data collection will arise when funeral directors discuss this topic with families.

The practice of racial categorization of Indigenous peoples in health data has always been rooted in the needs and desires of the United States federal government, itself embedded within a historical trajectory that has been shifting to a standard of self-identification.¹⁸ The OMB categories of “American Indian and Alaska Native” and “race” do not necessarily reflect how all Indigenous people understand their ancestry or their families, and the notion of collecting race as separate from ethnicity has been widely challenged by anthropologists and a 2020 Census working group on the issue.¹⁹ The OMB definition of American Indian and Alaska Native race in particular includes conceptual items such as “community attachment” that are difficult for data collectors to communicate or interpret and should not be neatly conflated with political status.²⁰ However imperfect, this current categorization of American Indian and Alaska Native race does allow for the approximation of populations that share some health determinants and resource pathways over time, in this case, access to healthcare in recognition of the federal trust responsibility.²¹ This report touches on how these historical issues have manifested in the funeral director’s office and connects these conversations to the current context.

In summary, this article will (1) describe determinants of racial misclassification on death certificates; (2) discuss these determinants in relation to changes in the funeral industry, death registration process, and social context that have occurred during the COVID-19 pandemic thus far; and (3) summarize the expected impacts of these changes and opportunities for prevention.

METHODS

This section briefly summarizes methods used in 2019 to analyze the role of funeral directors. Detailed methods covering all activities beyond this scope—including listening sessions with medical examiners and state vital records staff—are found in the full report.²²

Working Groups and SMEs

NCUIH staff began by gathering feedback from the perspective of urban Indian organization staff, tribal leaders, and a variety of SMEs, such as American Indian and Alaska Native funeral directors and epidemiologists. From October 2018 through November 2019, NCUIH participated in discussions with tribal leaders and four tribal epidemiology centers to gain a better understanding of how this issue affects their communities, existing work in the arena, relevant literature, and their ongoing research priorities. Informed by these activities and SMEs, NCUIH developed the series of questions and list of project activities.

Online Survey of Funeral Directors

Between May and September 2019, NCUIH conducted an online survey with funeral directors that covered professional history, experiences, and practices in completing

death certificates. Participants were informed about the funding and purpose of the survey and uses of their responses, and were provided contacts for NCUIH staff prior to consent. The anonymous survey was conducted via SurveyMonkey, which prohibited multiple entries from the same IP address. Respondents were given the option of providing contact information for follow-up.

Participants were recruited via snowball sampling from state licensing boards, funeral director associations, and national industry organizations who advertised via word of mouth, e-blasts, and newsletter articles. Directors and associations from every state were contacted, but not all passed along recruitment materials. A total number of 163 funeral directors from 36 states participated in the survey—about 1 percent of the total funeral director workforce in the country in 2018.²³ Results were used to identify common experiences and practices, though they are not necessarily representative of the industry or nation as a whole.

Response data was downloaded and imported into IBM SPSS for final analysis. Bivariate (Pearson) correlations were used to determine whether four common methods of identifying race, Hispanic origin, and tribal affiliation were statistically associated in this sample.

Key Informant Interviews

NCUIH conducted four key informant interviews with funeral directors between October and November 2019, with informants selected after they expressed interest on the online survey. Interviews probed funeral directors for more details on their experiences, and provided greater context for results from the online survey. Three of four informants identified as Native. Each worked in a different state, representing diverse rural, urban, eastern, and western areas.

A structured interview guide was developed with input and review by a Native funeral director SME. The guide asked about barriers and facilitators in identifying race, Hispanic origin, and tribal affiliation on death certificates. Interviewees were also asked to reflect on results from the online survey, with the goal of contextualizing these responses.

To analyze results of key informant interviews, NCUIH developed an *a priori* codebook with categories and themes of interest.²⁴ Transcribed interviews were content-coded based on the codebook themes, and verified by a second member of the team before results were summarized.²⁵ The findings most relevant to misclassification by funeral directors during COVID-19 are presented in the article below.

Return to Subject Matter Experts and Literature

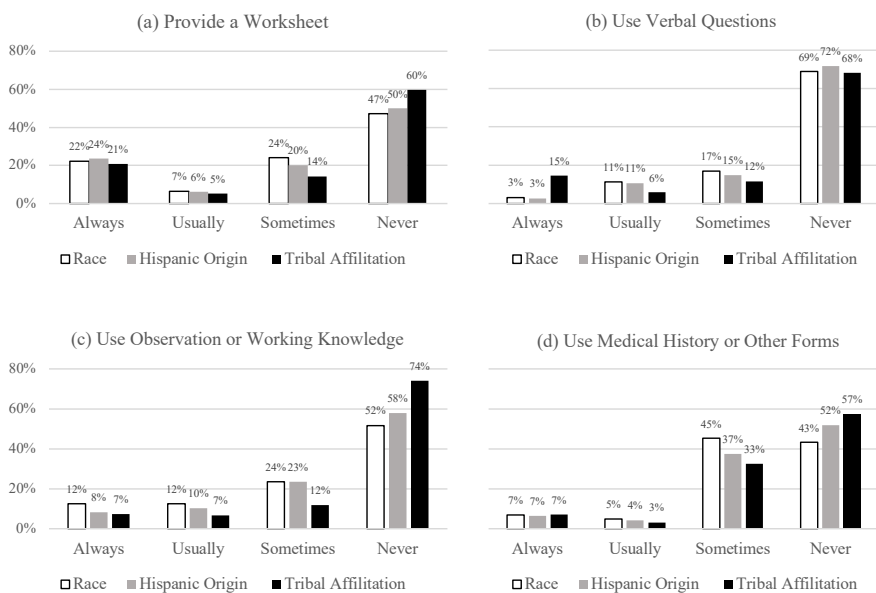
The COVID-19 pandemic began a month after initial analysis of interviews and survey responses. NCUIH expected that the policies and practices identified in 2019 would maintain relevance to racial misclassification, regardless of the time period. However, it was unclear how much an increase in death rates, the enactment of public health emergency powers, and/or physical distancing measures might alter the death registration system. In response, NCUIH took a two-part approach of (1) tracking changes in

death certification and the funeral industry, with a particular focus on New York State and New York City given their status as early COVID-19 hot spots; and (2) checking back in with funeral director SMEs to provide their perspective. Two SMEs were able to review early ideas for this paper and provide context on what has (or has not) changed in their work and jurisdiction since the start of the pandemic. This helped structure a discussion on mortality data quality around both current events and prior analysis.

RESULTS

Survey Responses on the Collection of Racial Data

Participants of the online survey reported that they “ask questions verbally to a family member or other informant” less frequently than any method when collecting racial data. Sixty-nine percent of participants report never asking verbal questions about race (see fig. 1). Instead, 48 percent reported using observation or knowledge of the family to complete these items. Copying from medical histories or other forms was most common, with 57 percent doing this at least sometimes.



Source: NCUH online survey of Funeral Directors (n=163).

Full options are: (a) Provide a worksheet for a family member or other informant to fill out.

(b) Ask questions verbally to a family member or other informant.

(c) Fill this section out based on observation or working knowledge of the family.

(d) Use information from the medical history or other forms provided by the hospital, medical examiner, and/or coroner.

Respondents could use multiple methods in combination, so percentages across methods may add up to more than 100 percent.

FIGURE 1. When completing the following demographic information sections on a death certificate, do you ever . . . ?

Some survey respondents used methods in concert, or used some sets of methods to the exception of others:

- ♦ Using any particular method to determine race was strongly and positively associated with using the same method to identify Hispanic origin and tribal affiliation ($p < .001$).
- ♦ Using “verbal questions” was negatively associated with using “observation or working knowledge of the family” ($p < .001$).
- ♦ Using a decedent’s “medical history” was positively associated with “providing worksheets for the family” ($p < .01$).
- ♦ Using a decedent’s “medical history” was also positively associated with “observation or working knowledge of the family” when recording race, Hispanic origin, and tribal affiliation ($p < .01$).

This indicates a difference between those who emphasize personal interaction (verbal, face-to-face interactions) and those who choose the most avoidant method (observation or knowledge of the family). It also indicates that a second cluster of behaviors are consistently relied on together, regardless of whether verbal questions are also used—namely, emailing impersonal worksheets and copying from medical histories or other forms.

When asked how often “Race” is left blank on a death certificate, 93 percent said this never occurs, but when asked how often tribal affiliation is left blank, 27 percent reported that tribal affiliation is always (6%), often (8%), or sometimes (13%) left blank. In a follow-up free response question, some respondents wrote that tribal affiliation is left blank if it doesn’t apply, because American Indian or Alaska Native race has not been selected. Other funeral directors said that tribal affiliation is left blank when:

- ♦ there is uncertainty or disagreement in families about which designation to use;
- ♦ the decedent is not an enrolled tribal member, or does not have documentation;
- ♦ there is no space on the form and/or the information isn’t required;
- ♦ a funeral director does not know how to record this, or is uncomfortable asking about tribal affiliation.

Interestingly, some of these reasons contradicted information from their state registrar, such as saying tribal affiliation is not an option or required. Some respondents attached their company intake forms to the survey, which lack a clear space for “tribal affiliation” despite its being available on the state certificate.

Interview Responses on the Collection of Racial Data

Though verbal methods were the least commonly reported method on the survey, each key informant utilized this method—possibly self-selecting for interview participation based on their own comfort in discussing race, or their own American Indian or Alaska Native identification. This subset of funeral directors each expressed a key set of preferred practices during interviews, which include always to ask about race directly, never to copy racial classifications between forms, and never to make assumptions about racial identity based upon appearance. If the family completed a death certificate worksheet outside of the office, interviewees said it was a best practice to

confirm the certificate item-by-item as they entered race, Hispanic affiliation, and tribal affiliation into the final electronic death registration.

These practices let the funeral director provide a full description of American Indian and Alaska Native race, respond to questions, and explain why this information is being collected. Funeral directors report that discussing race, tribal affiliation, and even veteran status can help a director get a better sense of the decedent's life. This helps the director identify financial benefits for which the family is eligible and to provide more personalized services. For instance, interviewees mentioned that when a funeral director knows about tribal affiliation or military service, they can help the family to secure burial assistance or final disposition options that the family was not previously aware of. This can ease burdens regarding logistics and costs.

Each key informant also stated that they rarely use hospital records or other forms accompanying the decedent to identify race unless the individual is unclaimed, unrecognizable with no next of kin, and/or a fetal death. Key informants indicated that there can be errors in hospital records, which is why they always verify race with family members, next of kin, or other informants. They also noted that funeral directors shouldn't rely on other forms of identification that travel with the body, such as human remains transport documents or "face sheets" from nursing homes (a photo identity record with demographics). They indicated that these documents can contain racial information that was collected by another professional based on sight and therefore are prone to biased assumptions of what different races look like. As one interviewee put it: "Usually doctors fill out as much information as they have and it's really not a lot."²⁶ This extended beyond race, as in one recent case:

We just did a burial for a gentleman, a person by the name of Jamie. It turns out this person is female, but all of her identification is male. So I notified the hospital and said, "You may want to look at your hospital records. This person is definitely genetically female, and I just talked to the daughter, and she said, "No, it's my mother. Her name is Jamie". . . So no, I don't think it's a good idea to go off those records, too. I think your best and most accurate source will be family.

Two interviewees mentioned procedures that are listed in the CDC *Handbook for Funeral Directors*—for example, the usage of a physical card with selections for different racial categories. There were mixed opinions on the utility of this procedure. One thought it can help if a family or inexperienced funeral director is uncomfortable or uncertain, while others thought that the formality of the procedure was a barrier to engaging with the family. One interviewee mentioned:

I don't think ["race cards"] are ever used. I've only ever looked at that in a book. I just want to hear what people say first and then work backwards, so it's a little easier that way: How do people identify themselves and really figure out how we're going to put that on the death certificate? . . . I get why they make the little cards so that we know. . . but it doesn't really jive (*sic*) with what we need to put on the certificates.

This sentiment—that families have a difficult time translating their identity into the labels available to them—was common with interviewees. As one survey respondent wrote:

Our experience has been that the families cannot define where they fit, so how are we to get it correct? I mostly feel like I am making a good guess. I do not think it should be the responsibility of the funeral home to collect this information. If it is important to be correct, then contact information could be collected by the funeral home and then contact should be made by a trained person.

Deathcare professionals are highly trained, but interviewees mentioned that their training generally did not extend to the social sciences or data collection. Asking about OMB race categories can dredge up concerns about data use, deeper family arguments about identity, or seem needlessly clinical to a grieving family. One Native funeral director mentioned a case he observed while training in 1980s, in which a man was being interviewed about his wife's race. She was eligible for tribal membership, but had chosen not to enroll. His trainer said, "Mr. Woods, your wife was black."

And the husband says, "No. We never went for that." The director says, "Well, what nationality is your wife?" The husband says, "Well, what are my choices?" . . . At the time, we have white. He said, "No, we never could pass for white. You said black. We're not black." And the funeral director says, "Well, we could check 'other.'" The husband says, "Well, check 'other' and put 'colored.'"

Although now processing these forms himself, the same funeral director noted, "That's the situation you have in this area, and I still see it a lot." He spoke of a recent series of deaths in the same family, starting with a woman in her twenties, who died in an urban area out of state.

She considered herself to be Native American. Her mother knew that she was Native American. Her father . . . Her father says, "Native American?!" . . . The wife says, "Yes, she was Native American. We're Native American." . . . The husband says, "I don't consider myself to be a Native American."

Though the woman's race was recorded as American Indian or Alaska Native, her mother's was not.

Fast forward. The grandma dies. I bury her. We put "Native American." Two weeks ago, I buried the mother . . . and the husband says, "I don't want 'Native American' on the death certificate. I want 'multi-racial.'"

This case underscores the complexity of asking a family unit that is rich with multiple viewpoints, identities, and relationships to determine race and tribal affiliation for one of its absent members in a time of extreme grief and stress. When navigating these conversations, funeral directors reported that they draw on the tools of their profession and emphasize comfort to families. Some reported choosing methods and procedures that emphasize individualized personal support and connection with their

clients. For example, one funeral director noted during an interview that he never records “Race” with a pencil in his hand so that the question does not feel impersonal. Likely though, a large number simply avoid these questions altogether to minimize either their own discomfort or that of their clients. As one survey respondent noted, “sometimes I don’t want to ask that.” Some interviewees reported that they expect that most of their peers are unaware of how to collect racial information accurately and may avoid asking this question altogether.

Responding to Family Questions and Concerns

On the survey, most funeral directors (74%) indicated that they receive questions from family members when they ask about a decedent’s race. Qualitative responses from the survey and interviews suggested that these questions most often center on why race is being asked about, or how it will be used. However, other common questions included if it is required to provide race at all; why a family member is showing up as white; “what counts”; “how much tribal is recognized”; and why “Hispanics are listed as white.”

Furthermore, 32 percent of funeral directors indicated on the survey that family members have expressed concerns, discomfort, or confusion about providing racial information. Approximately one-third reported family member concerns about reporting Hispanic origin and 16 percent reported concerns about tribal affiliation. Funeral directors indicated that family members have expressed a desire not to provide that information to the government, being ashamed about being American Indian or Alaska Native and/or Hispanic, not knowing how to report multiple races, not knowing the information is useful, or disliking the terminology on the form because it does not fully describe the decedent or the family. One funeral director wrote: “Most Hispanic people do not want to be listed as White.” Most survey respondents (74%) agreed that families would benefit from awareness about the importance of accurate death certificates, although rationale varied. As one funeral director wrote, “Most families feel the question of race is either irrelevant, offensive or unnecessary. I tend to agree. I must often excuse the race question.”

Few funeral directors expressed their own discomfort talking about these issues with families, with only 11 percent of survey respondents indicating discomfort talking about race or Hispanic origin and 13 percent indicating discomfort talking about tribal affiliation. Discomfort was only correlated with age and number of years in the profession, with younger and more junior-level funeral directors more frequently reporting comfort asking families about race, Hispanic origin, and tribal affiliation ($r = -.17$, $p < .05$).²⁷ This question may be strongly influenced by response, social desirability, and selection biases—funeral directors may have decided to participate based on their own comfort, or selectively not disclosed their discomfort based on the stated American Indian and Alaska Native health equity goals of the organization fielding this survey. The subset of interviewees generally did not agree with the aggregate survey results when it comes to comfort: each said discussing race can be uncomfortable, or that they think some colleagues may be uncomfortable.

Trainings and Handbook Materials

Every interviewee reported that they have not received education or training on how to discuss or collect race, Hispanic origin, and tribal affiliation information. Some wished that they had better education on culture or anthropology, through either schooling or continuing education. Though each understood the need for state statistics, none had been formally educated on the purpose or use of this data. Instead, interviewees generally indicated that on-the-job experience was how they learned that death certificates collect certain data and how to communicate that purpose to family members.

Results were more mixed in aggregate survey results. One-fourth of those surveyed said they have never received a training that covered demographic information. Funeral directors were divided on whether they would like more trainings; 55 percent said yes and 45 percent said no. Less than half (43%) of funeral directors were aware that the CDC NCHS provides an instructional manual, "Funeral Directors' Handbook on Death Registration and Fetal Death Reporting."²⁸ Less than half of those aware reported reading at least part of the handbook (or 20% of the entire sample). Write-in comments indicate that some found it informative and use it as a resource when certificates are incorrectly signed. Others reported that the handbook does not provide more information than they are already required to know as a licensed funeral director. One person pointed out that the handbook provides information that "most families are not wanting to digest after a loved one has passed away."

DISCUSSION

We can infer a few basic points from these survey and interview results. It is clear that funeral directors do not employ a standard method to collect race, Hispanic origin, and tribal affiliation for the purposes of death registration, nor is a uniform level of training or continuing education available. Both of these findings are crucial when considering how to implement trainings. This sample highlights a particular audience that is most likely to be the first to attend future trainings: namely, those willing to respond to a project about improving racial misclassification. Moreover, inconsistent methods and low levels of training among this potential audience suggest the possibility that future training materials would have a high impact.

Third, we find that while some methods for collecting race are used to the exclusion of others, some methods are only used in combination by these funeral directors. Those who ask about race do not use observation or working knowledge of the family (and those that rely on observation or working knowledge of the family never ask the question). Those who use forms or medical history may use them for a variety of purposes in combination with other approaches. Fourth, we note that the choice of method may relate to comfort and ease of completion, whether on the part of the funeral director or the family. Many survey respondents and interviewees reported fielding questions, concerns, discomfort, or confusion from families, and some interviewees questioned whether their colleagues remain avoidant or uncomfortable.

Lastly, and perhaps most interestingly, our interviewees were able to emphasize that asking the family about race directly is often helpful, though complex. These insights

have taken on new meaning against the backdrop of the COVID-19 pandemic. The remainder of this section discusses these findings in relation to recent changes in the death registration system and surrounding social context.

Time Lines, Medical Storage, and Physical Distancing

Early in the pandemic, people in New York City were dying of COVID-19 more quickly than funeral directors or hospitals were normally able to handle, delaying arrangements for death registration and final disposition. Meanwhile, hospitals reached capacity in their critical care units and morgues, creating an urgent gridlock. Given the well-documented racial and economic disparities driving death rates, the accumulation of COVID-19 deaths was especially taxing for hospitals and funeral directors that serve low-income, minority communities. One funeral home in a large, racially and economically diverse New York City neighborhood reported nearly ten times their usual caseload over a month, straining their capacity to serve families that face extreme grief and uncertainty.²⁹

Local spikes in death rates have been accompanied by more strict physical distancing measures, which initially slowed the bureaucracy of final disposition of human remains. At the height of New York City's spike in cases, the Department of Health cut its 24-hour in-person death registration in order to encourage physical distancing and limit virus transmission.³⁰ However, this exacerbated lags at funeral homes, lengthening a ten-minute process by hours. This was compounded with lags around family arrangements, autopsies, and postmortem testing, as well as coordination with cemeteries and crematoriums. To ease this burden, New York City extended the decedent storage available for families by two weeks.³¹ This created an entirely new workflow marked by new forms.³²

The resulting interim process made racial data from medical histories more salient in the death registration process than usual. Access to New York City storage was contingent upon the use of face sheets and a clinical worksheet. The clinical worksheet did allow for "Native American" to be selected, but with no ability for multiple races to be selected or tribal affiliation to be written-in.³³ One key informant specifically cautioned against the use of face sheets before the pandemic, suggesting that they can promote assumptions about race based on appearance and saying, "not only Native people, but some people who were black but they were very fair-skinned, it would be noted on there that their race was Caucasian. Or a lot of times, if they were Native American, it would be Caucasian or Black. That could be part of the problem, too." Lastly, hospital data is often less complete or accurate when collecting American Indian and Alaska Native race than death registration data.³⁴

Those who died of COVID-19 in hospitals did not have family members present to provide detailed histories, and sometimes had little cognitive presence themselves. When their remains were stored for longer periods, a funeral director may be contacted first to transport a body, well after the death has occurred and the paperwork created. This funeral director would likely be under immense stress as well in completing an electronic process lacking extensive arrangement planning with families face-to-face, as

usual. In this situation it would not be surprising if they relied more heavily on copying between forms with flawed underlying assumptions—practices that key informant interviewees specifically reject. Although families can later correct a death certificate, the fee to do so in New York is \$40.³⁵ In many jurisdictions, race is simply not listed on the family copy, so that many will be unaware of the error.

During the crisis, institutions in New York City reverted to methods that are culturally incompetent compared to usual and expected state practice, with the norm in crisis becoming a more limited racial selection based on forms, medical histories, and visual inspection. Funeral director SMEs in other regions with lower spread later said that these issues have not become the norm. Other states have proactively begun to monitor human remains storage capacity to avoid a bureaucratic logjam. Although interviews conducted in 2019 indicate that processing time lines is not often related to the methods a funeral director uses to record race, COVID-19 clearly changed procedures and time lines.

As such, conditions in New York City can be used as case example of how provisional death counts of urban American Indian and Alaska Native people are created by a strained system in a transmission hot spot. Though New York's early response may have stabilized, similar scenarios are possible in any American state or city depending on how outbreaks unfold.

Cause of Death Misclassification

Though racial misclassification on death certificates is a general issue affecting all American Indian and Alaska Native deaths, data quality during the pandemic is further compromised by cause of death misclassification. The COD and underlying cause of death are completed by the medical certifier on a death certificate, yet the medical knowledge on COVID-19 is almost completely new. Physicians are asked to record a COD and UCOD(s) that reflects their medical opinion, yet these opinions are still being shaped. Although there is no evidence yet, there is an assumption that COD misclassification does not necessarily cluster in any demographic—i.e., that any misclassified deaths are randomly distributed.

Early death counts were complicated by testing shortages—if a physician wanted testing confirmation to pronounce a COVID-19 death, this testing may not be a priority for someone if they were already dead (or close to death). This pronouncement also relies on a person seeking medical care from a physician early enough before their death. Many older and low-income minorities may not receive care early enough for this to happen, and the UCOD may be recorded as a chronic condition without the assumption of any infectious disease. Although postmortem guidelines for testing now exists (and is promoted),³⁶ collective decisions based on these COD reporting issues have already changed state reports.

In Minnesota, death counts doubled the week that UCOD guidance was adopted, stirring political controversy about emergency decisions that were based on medical opinions made without confirmatory testing.³⁷ A health official said that some deaths will inevitably “slip below the radar.”³⁸ In Colorado, about 25 percent of all deaths

changed after UCOD was reported differently, yet some proposed this reflected large *overcounting* of unrelated deaths in asymptomatic carriers.³⁹ One hypothesis is that misclassified deaths are distributed randomly, yet this hypothesis may be wrong if the cause of COVID-19 classification itself is tied to (1) testing access, and (2) access to quality medical care.

For American Indian and Alaska Native people living in urban areas, there are three facts that help ground COD statistics during the pandemic. First, it is clear that the earliest deaths due to community transmission were occurring in urban areas that have large American Indian and Alaska Native service populations, such as King County, Washington, and Santa Clara County, California.⁴⁰ Second, American Indian and Alaska Native individuals have generally had the largest age-adjusted hospitalization rate due to COVID-19 at 5.3 times the rate of non-Hispanic white persons at the time of publication.⁴¹ Third, hospitalizations for infectious disease were already more common than the general population for American Indian and Alaska Native elders, particularly for respiratory infections.⁴²

In short, COD misclassification may add a second layer of missing American Indian and Alaska Native deaths, apart from those missing due to misclassified race. If American Indian and Alaska Native people were among the earliest to be hospitalized and die in their cities, then racial gaps in data quality should be expected in cities where early COVID-19 deaths were not well-recorded. For the purposes of equity, American Indian and Alaska Native death estimates for COVID-19 should be reported alongside other causes of death during the same time period. The state of COD misclassification also underscores the benefit of preventing *racial* misclassification by funeral directors, as fewer sources of error clarify these statistics.

A Public Reckoning with Racism

Racism and its deadly consequences have reached a level of daily visibility in public discourse. It structures the social context in which funeral directors and families have these “data collection” conversations, regardless of the race of each. This context is salient for urban American Indian and Alaska Native families. The Minneapolis police precinct responsible for George Floyd’s death served the same area as the nation’s only federally subsidized urban housing complex with American Indian and Alaska Native preference, as well as a local Indian Health Service-funded health center.⁴³ These residents reported receiving messages from white supremacy groups during the protests.⁴⁴ On the other side of the country, an urban Indian organization—which provided some of the earliest SARS-CoV2 testing in the nation—has been repeatedly targeted with white supremacist graffiti.⁴⁵

In health care, there have been high-profile racist abuses of data, yet few clear messages that data can be used for the purposes of equity. In Albuquerque, home to one of the largest urban American Indian and Alaska Native populations,⁴⁶ the largest privately owned hospital system was exposed for using Census data to discriminate against American Indian and Alaska Native mothers. According to physicians, Lovelace Hospital had a policy of selectively cross-checking pregnant women if they

appeared to be American Indian and/or Alaska Native against a “pueblo list” upon admission. This list contained twenty-two local zip codes with a high concentration of American Indian and Alaska Native people, according to the Census.⁴⁷ Matches were immediately deemed to be “persons under investigation” (PUI) of COVID-19, regardless of symptomology, likely exposure, or whether the zip code was even a high-transmission zone. In fact, about half of these zip codes had lower transmission rates than the rest of the state, yet American Indian and Alaska Native mothers alone were tested and isolated. Some were isolated after giving birth, unable to meet their babies while waiting up to three days for testing results.

A whistleblowing doctor was quoted as saying, “We seem to be specifically picking out patients from Native communities as at-risk, whether or not there are outbreaks at their specific pueblo or reservation.”⁴⁸ This is the message most often transmitted when families seek health care or “provide data,” both of which usually occur in the weeks leading up to a funeral. Large cities like Chicago may be collecting data on American Indian and Alaska Native people, but resisting efforts to share or act on this when it shows disparities in virus transmission and testing.⁴⁹ At a time when racism is extremely visible in the public eye, American Indian and Alaska Native people have been shown many times that data can be used against them, with fewer examples showing that public health data can produce positive changes in their lives.

Families do not leave this social context at the door when a loved one dies. The funeral director operates within this context as well, given that they act as a proxy for the state when they collect death registration data. During 2019, each interviewee mentioned that discussing race with families can be uncomfortable for some funeral directors or family members. For example, some informants shared that families have not wanted to record items such as Hispanic origin due to a fear of tracking or persecution by the government based on immigration status. As a result, interviewees highlighted cultural competency in data collection as a key facilitator in collecting accurate information in 2019. NCUIH has not identified any resources, however, to promote this skill through training or educational requirements.

During the pandemic, it is likely that any discomfort, offense, or questions about race are likely to be similar to those expressed in 2019, but simply more salient in the minds of both funeral directors and family informants. Funeral directors have been working to implement new state trainings on infection control, procedures for storage of remains, and guidance on navigating postmortem SARS-CoV2 testing. However, NCUIH could not identify any training or guidance during the pandemic that cover procedures for accurately collecting any demographic data, let alone cultural competency when doing so. Cultural competency has become even more important when fielding family questions and concerns in the current social context, and high-quality data is needed more urgently than ever.

CONCLUSION

Based on a review of funeral director factors heading into the pandemic and changes in the death registration context since, NCUIH expects high levels of American

Indian and Alaska Native misclassification in COVID-19 mortality data. This is especially true for any deaths early in the pandemic (due to COD misclassification and distancing measures) or during any periods of high transmission and severe strain on funeral directors and hospitals. This will affect both COVID-19 and unrelated deaths.

Heading into the pandemic, key informants consistently reported that in-person, verbal verification is crucial to ensure that race on the death certificate matches a decedent's wishes. Yet it seems this is an uncommon or inconsistent practice. Verbal discussion prompts a funeral director to explain OMB categorization and the purpose of death registration data, and respond to any questions and concerns. This process is crucial for American Indian and Alaska Native people who may be overlooked by urban funeral directors or feel as if their family does not fit the history of OMB categorization.

Verbal confirmation may be increasingly rare during the pandemic, especially for COVID-19 deaths. Increased state storage of remains may affect the methods used to collect race, Hispanic origin, and tribal affiliation data for death registration by introducing new forms, increasing reliance on medical histories, or making the final dispensation process more hectic or impersonal. Funeral directors are making every effort to provide families with in-person services, yet institutional strain may further deemphasize in-person discussion. Racism is an ongoing public health crisis, and SMEs have reported that this is increasingly creating discomfort in both families and funeral directors when discussing OMB-mandated racial categories for the purposes of death registration.

A Path towards More Accurate Data

Simple practices by funeral directors are the key first steps to prevent misclassification. Never make assumptions about race, either based on sight, or knowledge of the family. Always ask about race, Hispanic origin, and tribal affiliation for every decedent. When race is listed on a form—even if it is not the final death certificate—use the most inclusive options in line with NCHS standards and allow for multiple races and tribal affiliation(s) to be recorded. Never copy race between forms, and always verify the registration with informants prior to submission to the state.

However, ensuring that these practices are consistently implemented is beyond the responsibility of individual funeral directors. Misclassification is produced through data collectors and state agencies together, whose methods are embedded within larger cultural trends of interpersonal and institutional biases. It will take active efforts to reverse these via policy changes and trainings. These may be mandated at the organizational, state, or national level, but clearly leadership is urgently needed.

Quality trainings can be quickly implemented, given that funeral directors have rapidly adopted an entire set of new policies, procedures, and trainings as essential last responders during the COVID-19 emergency. Ideally, training should go beyond “standard procedures” to include elements of cultural competency in data collection. This was identified as a best practice, yet clearly is lacking in the industry. Without this awareness, some funeral directors will likely revert to more avoidant (and less accurate) methods.

While prevention is implemented, there are short-term implications for COVID-19 data. First, racial misclassification should be disclosed wherever mortality data by race is reported. Second, governments should immediately share mortality data with tribal epidemiology centers and urban Indian organizations, which are well positioned to make use of data and help provide estimates on the extent of misclassification. Third, more can be done to promote state vital record coordination with community health experts—for instance, reaching out to tribes or urban Indian organizations when an American Indian and Alaska Native COVID 19 death is reported, given it may be representative of a larger outbreak that is poorly documented by death registration.

Lastly, American Indian and Alaska Native funeral directors, American Indian and Alaska Native statisticians, and American Indian and Alaska Native medical professionals all exist. Many are aware of best practices that should be followed and others that need to be revised, and they also can effectively communicate with their colleagues. During COVID-19, it is possible to support these professionals to address misclassification through trainings, awareness, and policy changes, providing the entirety of Indian country with better-quality mortality data during this pandemic and for years to come.

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