The Role of Forensic Science in Identification of Mistreatment Deaths in Long-Term Care Facilities:

Final Report

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TABLE OF CONTENTS

The Role of Forensic Science in Identification of Mistreatment Deaths in Long-Term Care Facilities

1. Introduction

Approximately 1.5 million Americans reside in long-term care (LTC) environments(1). This population often suffers from multiple illnesses and has significant risk factors for cognitive impairments, behavioral abnormalities, or functional limitations (2-11). Given the potential for having so many health-related problems, LTC residents are often dependent upon those providing their day-to-day care. The hope is that the caregivers and the LTC facilities have the interest of the residents in mind. However, there is research that suggests that there is mistreatment occurring in LTC facilities and that it may be severe and possibly widespread (12-17).

For decades, nursing homes have been plagued with reports suggesting widespread and serious maltreatment of residents, including abuse, neglect, and theft of personal property (18-22). A recent survey of 80 nursing home residents in Georgia found that 44% of the residents reported they had been abused and 95% reported they had experienced or witnessed neglect (23). While deeply troubling, these findings were not based on a random sample and unfortunately do not provide a reliable prevalence estimate. There is evidence of abuse and neglect from staff reports. A 1987 survey of 577 nursing home staff members from 31 facilities found that more than one-third (36%) had witnessed at least one incident of physical abuse during the preceding 12 months. Ten percent of the staff members surveyed reported they had committed such acts themselves. In addition, 81% of the staff reported that they had observed and 40 percent had committed at least one incident of psychological or verbal abuse during the same 12-month time period (14). Other surveys of nursing home staff have reported similar findings (13).

Regulatory and safety monitoring reports give additional insight into the scope of the mistreatment problem in nursing homes. The Long-Term Care Ombudsman program has reported that 10% of its complaints nationwide involve allegations of abuse, gross neglect, or exploitation, and 27% involve concerns about inadequate care (24). The federal Online Survey Certification and Reporting System (OSCAR) data system has reported an increase in deficiency citations related to abuse between 1988 and 2000, but these reports have been primarily related to facility processes rather than documented cases of abuse (25). Although the data cannot provide prevalence measures, they do suggest the potential severity of the problem. For instance, an analysis report of OSCAR data in 2001 by the Special Investigations Division of the House Committee on Government Reform asserts that abuse of residents "is a major problem in U.S. nursing homes" (26). Ten percent of the nursing homes in the U.S. were cited for abuse violations that caused actual harm to residents or placed them in immediate jeopardy of death or serious injury. The report concluded that during a two-year period, nearly one-third of all certified facilities had been cited for some type of abuse violation that had the potential to cause harm or had actually caused harm to a resident. These numbers and assertions may even underestimate the problem. Investigations conducted by the Government Accountability Office (GAO) also found that one-fifth of nursing homes during 2002 had actually harmed residents and the periodic inspections, whose results generate OSCAR data, have failed in identifying serious deficiencies (27,28).

In summary, while there have been no definitive studies on the prevalence of abuse and neglect of nursing home residents, there is certainly credible evidence that suggests that the problem is serious and widespread. Many questions remain unanswered, including risk factors and markers of severe or fatal mistreatment. Until recently, there was no process in place to

systematically review nursing home deaths and investigate for signs of abuse or neglect. A new state law gives us such an opportunity. In response to several high profile deaths in LTC facilities, the State of Arkansas enacted a law in 1999 that gives Arkansas county coroners legal access to LTC facilities following the death of a resident. Specifically, Act 499 of 1999 states:

> In all cases of death of a long-term care facility resident, the long-term care facility shall immediately report the death to the appropriate coroner. The report is required regardless of whether the facility believes the death to be from natural causes or the result of abuse, sexual abuse, or negligence, or any other cause…The medical examiner or coroner shall accept the report for investigation and upon finding reasonable cause to suspect that an adult has died as a result of abuse, sexual abuse, or negligence shall report his findings to the police and the appropriate prosecuting attorney.(29)

Mark Malcolm, who has served as Coroner for Pulaski County (PC), Arkansas since 1995 and as Chief Deputy Coroner eight years prior to this appointment, played an instrumental role in this law's development and subsequent passage. In his testimony before the U.S. Senate Special Committee on Aging on March 4, 2002, Mr. Malcolm reported that in less than three years of conducting these investigations, his office identified at least 56 nursing home deaths in PC that were suspicious for neglect or abuse. In relation to these deaths he stated:

> We have seen dinner plate-sized bed sores with infected and dying tissue, infected feeding tubes, rapid and unexplained weight loss, dehydration, improperly administered medications, and medication errors that resulted in death. We have found basic needs such as general hygiene and dental care neglected, urine and fecal matter dried on bed linens and in diapers left unchanged for hours. We have seen a patient whose care had been so poor that a mucous growth formed on the roof of her mouth and when it finally sloughed off, she asphyxiated and died. When we arrived at the facility to examine this woman, ants were crawling on her bed and body.(30)

At the conclusion of this testimony, Mr. Malcolm states that deaths such as those mentioned above would go unreported and unnoticed if this law was not in place.

In an effort to understand the implementation and effects of this law, as well as to gather information about the current state of forensic investigations of deaths of LTC residents throughout the U.S., in late 2002, our research team began a three-phase exploratory project entitled, "The Role of Forensic Science in Identification of Mistreatment Deaths in Long-Term Care Facilities." We used a mixed method approach to examine the law's enforcement, effects

and generalizability. For two of these phases, we focused exclusively on Pulaski County, Arkansas. The entire geographic focus was PC for several reasons. As discussed above, Mark Malcolm was highly involved in the construction and passage of this law. In order to understand under what circumstances this law came about, we chose to speak with an individual who was involved in this capacity. In addition to this, the day the law went into effect, July 1, 1999, the PC coroner's office began conducting LTC death investigations. Since that day, this office has conducted over 2,000 LTC death investigations, a number not possible for any other Arkansas county as PC is the most populous county in the state. These factors make this office's knowledge and experience unique to other offices in the state. For this project, first, we conducted exploratory interviews with Mark Malcolm and his staff of four current and former investigators for Pulaski County. These one-on-one interviews mapped the process of the nursing home death investigation procedures, gathered impressions about markers that might indicate mistreatment, and outlined barriers and facilitators to conducting these investigations. The results of this phase of the project are discussed in Section 2. We also collected and abstracted nursing home death investigation reports from PC for the year 2001 (n=495), comparing the 21 decedents referred for further investigation and those who were not referred. This project also included a pilot attempt at linking these decedents to their nursing facility's Minimum Data Set (MDS) in order to locate resident and/or facility-level factors that may indicate higher risks of mistreatment. The results of this analysis are discussed in Section 4 of this report.

Finally, we conducted a series of focus group interviews with medical examiners, coroners and geriatricians from across the country in order to determine the current state of forensic investigation of nursing home deaths and how abuse and neglect leading to mistreatment deaths might be identified. The results of these focus group interviews are discussed in Section 3.

2. Exploratory Interviews

The first phase of the project involved interviews with Mark Malcolm and his current investigators, as well as one former investigator. The main goal was to achieve an understanding of the background, implementation, and outcomes of this law. In Section 2.1, an overview of the methods is described. Section 2.2 offers background information on the development and passage of the law. In Section 2.3, the PC investigation process is laid out. Next, Section 2.4 offers a number of markers for mistreatment. Section 2.5 addresses the respondents' perceived changes over time since the implementation of the law. Sections 2.6 and 2.7 concern the participation of other Arkansas county coroners in enforcing this law, as well as general advice to other coroners interested in successfully conducting investigations in their counties. Finally, Section 2.8 deals with what the respondents feel might allow them to conduct more thorough LTC death investigations.

2.1 Design and Methods

2.1.1. Setting and Sample

In order to more fully understand the development and outcome of this law, exploratory interviews with Mark Malcolm and his staff of four current and former investigators for PC were conducted. During a site visit to the PC Coroner's office in January of 2004, interviews were conducted with Mark Malcolm and his three current investigators for PC. In February of 2004, a former PC investigator, now working in another Arkansas county as a deputy coroner, was interviewed via telephone. Four of the respondents were white, one was African-American; four were male and one was female. Respondents had been working or had worked in the PC Coroner's office from one to 17 years.

2.1.2 Data Collection

These interviews focused on the circumstances that led to the law's development, the LTC death investigation procedures, markers that may indicate mistreatment, and the impeding or facilitating factors in these investigations. A draft of the interview schedule was developed prior to the first site visit by the entire research team. The information gleaned during the initial site visit and preliminary analysis of investigation records (discussed below) were used to further develop the interview questionnaire and to focus on issues raised in the preliminary analysis. Specifically, when abstracting 2001 investigation records, close attention was paid to the text of referred cases in an attempt to understand, from the written reports, what prompted suspicion on the past of the investigator. With most of these cases, it was apparent (e.g., numerous pressure sores, coroner's office not being notified of a death in a timely manner); however, that was not always the situation. During the interviews, we asked the respondents who conducted investigations during 2001 (n=3) to look at one report they had written in which the reasons for referral where not obvious to the researchers, and to elaborate on why they referred the case.

Prior to conducting the interviews, the questions were reviewed for content and face validity by the entire research team. The final interview contained the following general topics:

- the circumstances that served as the impetus to the law's development;
- the procedures involved with conducting a LTC death investigation;
- impressions about markers that might indicate mistreatment;
- barriers and facilitators to conducting these investigations

The interviews ranged from approximately 40 minutes to two hours in length and were tape-recorded.

2.1.3 Data Analysis

Interviews were transcribed verbatim. Members of the research team reviewed transcripts. Using a primarily immersion-crystallization approach to content analysis,(31), multiple readings of the transcripts were carried out until consensus was reached on salient themes and issues. After each reading, interpretations were discussed. Any differences of opinion were resolved through corroborating/legitimating.(31) Although other issues arose, six major themes were ultimately identified and will be discussed in this report:

- the general investigation process;
- markers for mistreatment;
- perceived changes in the process over time;
- participation by other Coroners' offices;
- advice to other offices;
- potential improvements in the process.

Each theme is discussed below.

2.2 Development and Passage of the Long-Term Care Reporting Law

Beginning in 1992, a few families of deceased LTC residents began contacting the PC Coroner's office with questions regarding their family member's stated cause of death. The coroner felt it necessary to investigate; however, efforts to obtain medical records from the facilities regarding these decedents were often met with resistance, which necessitated the obtaining of court orders. These families often retained attorneys to represent them, which brought media attention to the situation. This, in turn, began generating a public awareness of LTC mistreatment. More families made complaints and ultimately, the coroner and his investigators walked out of one LTC facility with several dozen files associated with complaints.

Concerted efforts at prosecution began. The coroner's office, along with the Arkansas Attorney General, decided to focus on cases where the ability to prosecute and convict were highly probable. From 1994 to 1998, seven bodies were exhumed and full investigations were conducted, which included autopsies. Of these cases, there were six convictions and one undetermined death. Of the convictions, four were asphyxial deaths, one involved a medical error, and one was declared a homicide (with a deliberately administered overdose).

With these six convictions, continued media attention on the PC Coroner's efforts, and media attention on other mistreatment cases in Arkansas, the PC coroner felt that there clearly was a problem with LTC mistreatment and that the time was right for legislative action. He, along with his chief deputy coroner and the counsel for the Office of Long-Term Care, constructed a bill that would grant all Arkansas county coroners access to LTC facilities following the death of a resident. The bill became a law with little to no opposition and PC began conducting death investigations in LTC facilities the day the law went into effect, July 1, 1999. In regard to this process, one respondent stated:

> If the nursing home industry knew what a coroner's investigation was when we asked for that law, it would have been a whole lot more difficult …No lobbyist from the industry showed up, no owner showed up… And I never did know, still don't know if they thought [we] wouldn't get it done or if they thought, "It doesn't make any difference. If [they] want us to call, we'll call…" And had they known, had they taken ten minutes in the hallway of the capitol and said, "Now exactly what is a coroner's investigation," it would have been trouble. But as it was, we slid in there, got it done, got out.

2.3 Pulaski County's Investigation Process

In addition to this law, PC has developed General Order 108, entitled "Investigations Into the Deaths of Long-Term Care Patients," which specifically outlines the investigation process. On-site investigations are conducted on nearly every death in LTC facilities. For instance, in 2001, there were 533 nursing home deaths in PC. Of these, 92.9% (495) had on-site investigations. The primary reason for the investigations is to determine if decedents received an

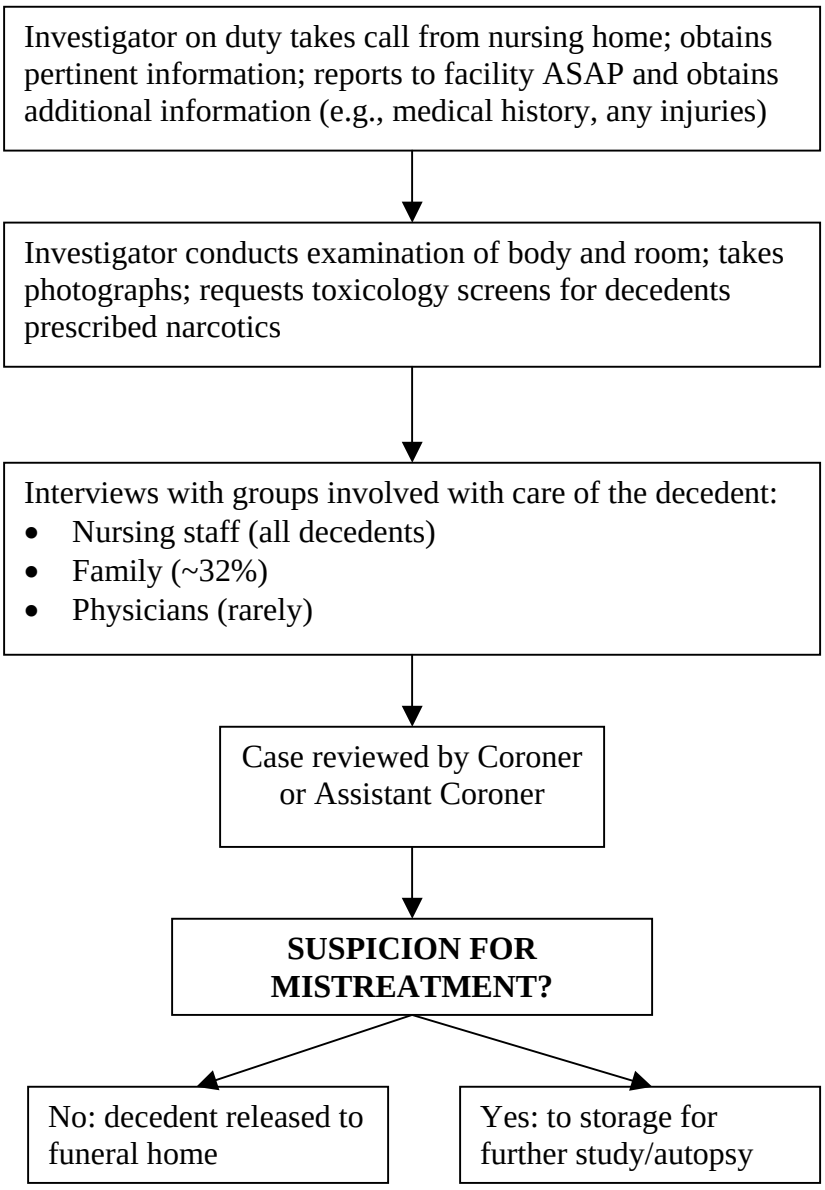
acceptable level of care while residing at the facility. When a death occurs, the facility is required to contact the county coroner's office. The deputy coroner on-call takes particular information about the decedent such as decedent's name, time the call was received, time of death, attending physician, a brief medical history, and at which LTC facility the decedent resided.

The investigator then reports to the facility, where s/he views the decedent's medical records and is informed of any particular issues. An examination of the body and scene then occurs: any eye hemorrhages are noted, the weight is compared to that on the records, injuries – reported or unreported – are noted, and any level of rigor mortis is noted. Investigators also observe the cleanliness of the room, as well as the facility in general (discussed further below).

Interviews with groups involved with the decedent are also conducted. Because LTC staff members are involved in the day-to-day care of the decedent, interviews with this group are necessary and always occur. Open-ended questions are asked regarding the decedent's health history, recent changes, and care received. If family or friends are present (family members were spoken to in 31.7% of the cases in 2001), their impressions of the general care provided are obtained. One respondent stated that, if the decedent was cognizant (i.e., not suffering from dementia or Alzheimer's) s/he asks the family member how the decedent perceived their own care. Physicians, if available, may be interviewed. Their role is so give focused medical information about what is in the chart, and, if they have been attending to the decedent for years, offer specific information about the decedent's condition. However, all the respondents indicated that physicians are rarely present during the investigation and, although the investigator may call the physician's office for particular information, this rarely occurs. Finally, the decedent is

photographed, without clothing, and then released to the designated funeral home if no problems arise during the investigation. Exhibit 1, on the following page, outlines this process.

Exhibit 1: Brief Outline of Pulaski County Coroner's Office Nursing Home Death Investigation Process



2.4 Potential Markers for Mistreatment

The majority of coroner investigations do not raise suspicion for mistreatment. However, particular findings, or impressions, sometimes lead to referral for further investigation by other offices. Four categories of factors, or markers, were identified from the interview data. The first category involves the physical condition of the body and attention to detail. Several examples were offered that may indicate a poor quality of care associated with either neglect or abuse, such as adult diapers not being changed regularly, bruising on residents who were non-ambulatory, and undocumented injuries or fractures. Three respondents also specifically indicated that the history of family attendance should be noted, since investigators felt that more attention was given to residents whose family visited regularly.

The next category involves characteristics of the facility. The assumption made by respondents is that if the facility and the rooms are not clean, there is a strong possibility that basic health care services are also not being provided. One respondent stated, “If somebody is not providing even a basic housekeeping service, then how can you really be sure that they’re providing skilled medical care?” Other indicators of poor housekeeping include overflowing trash cans, the smell of the cafeteria at all hours, and food left on trays for long periods of time.

In addition to not providing basic housekeeping services, a facility having a history of providing poor care may also make investigators pay close attention. One respondent’s referred case makes this point. When looking at the investigation report, the respondent stated that what pushed this case to referral was first, the odor emanating from the numerous pressure sores, and secondly, the facility in which the decedent had been residing. This was an institution that had severe problems in the past, which influenced the investigator’s decision to forward the case.

A third category involves inconsistencies: 1) inconsistencies regarding what is in the records, what is stated during the interviews, and/or what is viewed by the investigator; 2) inconsistencies between what different groups (nursing staff versus family) are stating about the care received; and 3) inconsistencies between the reported time of death and condition of the body. As an example of the first, one respondent relayed the details of an investigation that was ultimately referred:

> I had all my paperwork in front of me, I had turned to go down the hall...the nurse stopped me and said, "Oh, by the way, don't be startled when you see her. She's got a couple of bruises on her…She took a tumble out of the bed or something, so don't be startled." I walk in the room and there are bruises all over her face and down her neck…I walked back down the hall and said, "I need incident reports, I need dates that this happened, I need everything you have on it." They told me one date, I had report on another date. I had a report that supposedly she'd fallen a couple days prior, and when I'm reading the report, it said, she had a rug burn on her head. That didn't look like a rug burn.

Finally, particular behaviors of, or comments made by the nursing staff may alert the investigator to the potential for problems regarding a death. The initial impression sets the tone for the entire investigation:

> Your initial entry into the nursing facility, a lot of times, will let you know what kind of call it's going to be. If they meet you at their front door, it's usually not a good thing…there's something going on that they're trying to guide me to or guide me away from.

Staff members who will not accompany the investigator to the room or those who make themselves unavailable also make investigators take notice. Another signal are staff members who express little concern about the resident and/or lack knowledge about the treatment plan of a patient for whom they were providing primary care:

> If you treat this person every day, you should be able to give me a general idea of what his medical condition is or what his concerns are, what his needs are. But when I ask you a question about a patient that you're supposed to be the primary care giver on, and you tell me to hold on, let me research my notes, that's not very attentive.

Vague or short responses such as, "I just work weekends," "This isn't my patient," "They've had a little fall," and "They've taken quite a few tumbles," may signal an inadvertent attempt to

evade pointed questions. Staff members may also be purposefully evasive by making calculated choices about what they want and do not want to reveal:

> The family will state, "Well on this day and this day, they said he fell." You go back and ask the staff and sure enough, it was there. I will ask them, "Why wasn't this disclosed?" "Well, that's not a part of his medical record, that's a whole separate issue," which technically it is, but they know what we're after.

Poor documentation and evasiveness were issues in at least one of the cases referred for further investigation in 2001. When looking at the investigation report, the respondent stated that two referrals had been made on the particular case. The first was made after the initial investigation. The decedent had several pressure sores on the buttocks and lower legs; however, after this investigation and referral, an anonymous phone call was received from a former employee of the facility who stated that parts of the decedent's health history had been undocumented and not revealed during the initial interview. The case was again referred for further investigation. Exhibit 2, on the following page, summarizes these four categories.

Exhibit 2: Potential Markers for Mistreatment

Physical Condition/Quality of Care

- Documented but untreated injuries
- Undocumented injuries and fractures
- Multiple, untreated, and/or undocumented pressure sores
- Medical orders not followed
- Poor oral care, poor hygiene and lack of cleanliness of resident (e.g., unchanged adult diapers, untrimmed finger and toenails)
- Malnourished residents that have no documentation for low weight
- Bruising on non-ambulatory residents; bruising in unusual locations
- Family has statements and facts concerning poor care
- Level of care for residents with non-attentive family members

Facility Characteristics

- Unchanged linens
- Strong odors (urine, feces)
- Trash cans that have not been emptied
- Food issues (cafeteria smells at all hours; food left on trays)
- Past problems

Inconsistencies…

- Between the medical records, statements made by staff members, and/or what is viewed by investigator
- Between what the different groups interviewed state
- Between the reported time of death and condition of the body

Staff Behaviors

- Staff members who follow the investigator too closely
- Lack of knowledge and/or concern about a resident
- Evasiveness, both unintended and purposeful, verbal and non-verbal
- An unwillingness of facility to release medical records

2.5 Changes over Time

When the interviews were conducted, investigations had been occurring for more than four years, allowing for reflections regarding what had changed since implementing the law. Overall, the respondents felt that the consistent presence of the coroner's office had done two things. First, it helped to create a decent working relationship between the coroner's staff and LTC staff at the facilities, which had not always been the case:

> There was a time in the beginning, it was totally confrontational, it was totally antagonistic…They hated us, we knew it, and so we asked the questions no doubt with the tone that, "We understand that you don't want us here, but we're here, and so this is the way it's going to be." It took those first two years to really get the point across. "This is not something new and when the newness wears off, we're not coming anymore." And I think the other thing that they really began to understand was it's not that big a deal. "They're going to come in, they're going to take some pictures, they're going to do an exam, they're going to go through the charts, they're going to ask some questions, we answer the questions and they're gone." Now that everybody knows the drill, it's a relatively simple process.

Another outcome, which was unintended, was the sense that the consistent presence of the coroner's office had helped improve the overall quality of care in the facilities. In the opinion of the respondents, because the nursing staff knows the coroner will investigate nearly all deaths, providing good care becomes the "path of least resistance." One respondent stated:

> In the beginning, it was all about finding poor care…It was getting us access to the homes, seeing the bodies before they left the facility, seeing them within a very few minutes after they died so that there are no changes…I think in the beginning it was always about finding the poor care and I think today, it probably still is. But I think what has happened, over time, because we found so many horrific cases in the beginning, I think that today, it's more of a deterrent than it is anything.

Another reiterated this by stating: "They know we're coming. They know that we're going to be looking into them…I think that makes them take better care of them." To support this claim, respondents stated that the general appearances of the bodies and scenes have improved over the last five years. In addition to this, the percentage of cases referred to the AG since 1999 has decreased. In 1999, there were 21 referrals from July 1 to December 31. From 2000 to 2002, annual referrals decreased from 23 to 21 to 19, despite an increasing number of LTC beds. In 2003, there were only 6 referrals. Other indicators of care improvement regard feedback

provided by the coroner to the facilities. One respondent mentioned education about oxygen masks:

> We had a problem for a long time until the nursing facility took care of it on their own, after gentle prodding from…our office, of them putting oxygen at inappropriate amounts on patients…You can do damage that way. The nursing staff generally didn't know that…But we were able, as an office, to educate them and let them know that this was a concern of ours and get them on the right track. Now, it's a rarity that we see an oxygen delivery problem.

Another respondent mentioned medication errors:

> If there are drugs in our person that aren't prescribed to them, then we can go and get in the other medical records and see if it's prescribed to the person in the other bed…That happened five or six times right away, and then as soon as we started bringing it to people's attention, boy, we cleared that drug problem up pretty quick.

2.6 Participation by Other Coroners' Offices

The state law requires that all LTC deaths be reported by the facility to the appropriate coroner. The coroner should then accept the report for investigation. Although we are not aware of the exact number of county coroners in Arkansas (n=75) receiving and accepting these calls, and of those, who are conducting investigations, according to the respondents, the PC office is one of few carrying out the law with consistency. The GAO recently conducted a study on the outcome of referrals made to the Arkansas Attorney General and the Office of Long-Term Care. They found that between 1999 and 2003, all but four of the referrals made came from the PC Coroner's Office (32). This is an indication that few investigations are occurring in other parts of the state. There is an acknowledgement that barriers do preclude investigations. For instance, some respondents indicated that other coroners and their staff may not have the necessary training to conduct these types of investigations. Another major barrier involves manpower. The PC office has a full-time coroner, and four full-time staff members (one chief deputy coroner, two deputy coroners, and one office assistant) whereas most other offices are operated by part-

time coroners and part-time staff. PC has simply taken on the additional work without additional funding or staff, something other offices may not be willing or able to do.

Another issue concerns whether the coroner is elected or appointed. In PC, this is an appointed position, one of two in the state of Arkansas (the only full-time appointed position). One respondent felt that enforcing this law could cause some conflict with the same people who elect that individual, especially in smaller communities where the network of social relations may be more connected than in more densely populated counties, such as PC.

However, some respondents stated that low participation may have to do with a general lack of concern about elder mistreatment and elders in general:

> There are some coroners in the state that I've talked to that…don't care. It's more of an interruption of their day…When the law was enacted, it was more of something they were made to do versus something they should have wanted to do…Who are you looking out for? Are you looking out for yourself? You looking after somebody else?

2.7 Advice to Other Offices

Because the respondents had first-hand knowledge of the investigation process, all were asked what advice they would offer to a coroner's office interested in conducting these types of death investigations. While concrete suggestions were offered, they were often embedded within behavioral and attitudinal themes. First, in these discussions regarding advice, a general theme of consistency arose. There must be consistency in how investigations are conducted, or in other words, how the law is applied. Investigations should occur every time a death is reported. If not, the potency and legitimacy of the law is diminished. One respondent stated:

> You have to stick to your guns. You not only have to follow the law as it's written, but you have to make sure that everybody else does, too. You cannot one day say, "That's okay, we'll come back and get that record tomorrow." You can't do that for anybody because the minute you do it for one home, every home is entitled to that. You can't fight a subpoena request of this home and not fight for this one just because you probably know they're a good home. It has to be consistent, every fight you get into.

This element of consistency is also written into General Order 108. "LTC investigations shall be carried out in the same manner as any other death investigation conducted by the PC Coroner's Office." Beyond the fact that this is written policy, all of the respondents cited this, and at times, emphasized it, which indicates that the policy is valued. One respondent stated, "I treat my nursing homes just a serious as I do a homicide, so to me, they're one and the same. You don't give special care to either one; everything is special."

Another theme was that of persistence. Persistency must occur during the process as well because it makes the facilities realize the importance and permanency of the law. One respondent noted that some facilities were not receptive to the presence of the coroner's office and that it then became the role of the assistant chief coroner to be "the enforcer:"

> That is where I think we met most of our resistance. There was obviously nothing they could do about it and they knew it. [Assistant Chief Deputy's] role was always the enforcer. He would go in there and just let them know, "This is what we're going to do and this is how it's going to be done. You're not going to be able to do anything about it, so you can just get over it." [And] …I hate to say it, but that's kind of what these people needed...They would try to push you around, so you had to get in there and put your foot down…They needed to know that you were there and you meant business and if they did something that was wrong, or if there were some neglect issues there, you were going to be…all over that. There were going to be some repercussions for their actions.

In regard to this theme, one respondent specifically mentioned delays in reporting and the problem they can pose if tolerated:

> Nobody can be allowed to delay the reporting; it doesn't matter who it is, doesn't matter why they delayed, they go to the prosecutor, first time, no warning, no nothing. If they're going to delay the report and not call you ten minutes after they're found but an hour, it goes to the prosecutor; it has to every time. And it's the only way that you get to where we are now.

Certainly, what helps in this office's ability to be consistent and persistent is the existence of this law – the law allows this office access to all nursing homes deaths. The law itself gives this office jurisdictional authority within the facilities. The boundaries of this law protect coroners:

> Anytime that you think somebody is stepping out, you use that law as a tool…you can't do anything that's not within your bounds to do, but it sure helps to know what the bounds of your jurisdiction are, what

> you're abilities are. You might walk right up to the edge one day, but as long as they know that it's always fair, it's always the same, you're going to be fine.

As was discussed above, LTC facilities, as well as family, may not initially welcome investigators – the facilities due to the additional layer of regulation, families because it may seem alarming, unnecessary, and/or intrusive during a time when privacy feels necessary. However, one respondent felt this tension could be alleviated with open communication about the law and its intentions:

> I would go into these nursing homes and obviously be very polite and speak to their administrator…Speaking with the family so that the public knows that you are there and what your role is and that they understand that we're not there to degrade their loved one or take these pictures for no reason. They understand that we're there to protect their family member and them if they were ever to be put in a nursing home as well.

One suggestion made by respondents that may be more difficult to reproduce is generating a commitment to the law and the investigations. In other words, possessing the attitude that conducting these investigations is the right thing to do. Given the lack of additional funding attached to this law, an additional workload falls on the existing staff. In PC, this means hundreds of additional investigations per year, which has meant a 20% added workload. For these respondents, this was a moot point as they felt that the extra work did not negatively impact other office duties and that the work they put into implementing the law was well worth it. As one respondent said, "I feel like if we find one out of 2000, then I think we've done our duty. The law was in place to help that one." In addition, all respondents indicated that conducting these investigations brought them satisfaction in that they felt they were protecting the elderly. Each of the respondents clearly expressed a sense of pride and respect in what they were doing, and suspected that ageism had something to do with the lesser commitment to these issues outside of PC:

> One of the things that we pride ourselves on here versus all the other coroner's offices in this state is…treating our nursing home investigations as seriously as we do our homicides, our motor vehicle accidents, everything else. Notoriously, I think we take in our nursing home patients or our older

> generation, just shove them away there and say, "You all have lived a good life, you've done well, just get old quietly and pass on and you'll be alright." We're not going to do that …You're a person that lives in this county. We're going to treat you with the same respect that we treat anybody else. And you're going to get every investigation of your death that you deserve. Just because you're in a nursing home, doesn't mean anything.

2.8 Suggested Improvements in the Process

Respondents were asked to discuss any additional information or procedures that would assist them in making determinations regarding care quality. Overall, the respondents felt that the investigational process, as structured, gives them the information they need. However, one suggestion was offered. At present, each investigator is on call for 48-hour shifts. That investigator on call takes the calls and conducts all the investigations the coroner's office is involved with during that time, such as motor vehicle accidents and homicides. The coroner or the assistant coroner may assist if the volume of cases is too great. This respondent felt that more personnel, coupled with a reduced shift, would help alleviate some of the fatigue that can come with that schedule.

Other suggestions were made regarding information obtained after the on-site investigation, with toxicology screens and autopsies. At present, all decedents receiving narcotics get toxicology screens. However, several respondents mentioned that increasing the number of these screens would lead to locating incorrect dosages. An increase in autopsies was suggested. At this point, all cases where mistreatment is suspected are sent to the Office of Long-Term Care and the Arkansas Medical Examiner for further investigation. If there is a determination that an autopsy is necessary, one is conducted. However, one respondent felt that having the ability to conduct autopsies on not only those cases, but also on a set interval of cases (e.g., every 10^{th} case) would be useful. These autopsies would not be conducted in an effort to detect

mistreatment, but to better understand cause and manner of death, especially in situations of sudden death. In other words, use autopsies as a learning tool.

2.9 Summary

From development to enforcement, this particular office has maintained a strong *commitment* to this law. In their implementation and enforcement, they use the *authority* granted them via the law to maintain both a *consistent* and *persistent* presence in the facilities. The perception of the coroner and his staff is that this presence has not only helped to detect poor quality care, but it has also improved the overall quality of care and possibly prevented some mistreatment in the future. These findings provide further understanding of systematic death investigations in LTC facilities, and suggest a positive impact of this law on awareness of LTC mistreatment and quality of care. However, similar findings in offices of other coroners and investigators will be unlikely without their firm commitment to enforcing such a law.

Another phase of this project involved focus groups with coroners, medical examiners, and geriatricians. While some of the themes identified in the focus group analysis are similar to those identified during the analysis of the above interview data, there were differences in how focus group participants viewed the problem of institutional mistreatment. The following section discusses the focus group results.

3. Focus Group Interviews

The second phase of this project involved a series of focus group interviews. Four of the focus groups included medical examiners (MEs) and coroners. The goal of these focus groups was to determine the current state of forensic investigation of deaths of nursing home residents, to ascertain barriers to such investigations, and to identify potential indicators of abuse and neglect that could be used in a system of forensic investigations. Two other focus groups were held with geriatricians. The purpose of these focus groups was to identify indicators or markers that might suggest abuse or neglect and to discuss issues related to reporting potential mistreatment of nursing home residents.

Section 3.1 provides a brief overview of the focus group methods. A discussion of the findings follows. Analysis of the focus group interviews with MEs and coroners identified several themes in response to our study questions. In particular, the analysis revealed several impediments to increasing forensic investigations of nursing home deaths. They may be broadly categorized into attitudinal and administrative barriers and knowledge deficits. These findings are discussed in Section 3.2. The analysis of the focus group interviews with geriatricians identified two major themes – potential indicators of elder mistreatment in nursing homes and barriers to reporting of suspected cases of abuse and neglect. An overview of the focus group interviews with geriatricians and the findings about barriers to reporting are discussed in Section 3.3. Section 3.4 presents potential markers for abuse and neglect, based on the views expressed in both the ME and coroner focus groups and the geriatrician focus groups. Section 3.5 focuses on the implications of the focus group findings and how the role of forensic investigations might be enhanced to address or prevent abuse and neglect of nursing home residents.

3.1 Design and Methods

The research team developed participant consent forms, moderator guides with key topics and more specific probes, participant surveys, and recruitment materials for both sets of focus groups. Samples of a Moderator Guide and Participant Survey are included in Appendices B and C. Coroners and medical examiners (MEs) were recruited before and during the Annual Meetings of the American Academy of Forensic Science in both 2003 and 2004. The recruitment was intended to produce a mix of MEs and coroners, of statewide local MEs, and of large and small, urban and rural ME and coroner offices. Geriatricians were recruited before and during the 2003 Annual Meeting of the American Geriatrics Society. This group was purposively selected to secure participation of geriatricians who had expertise in forensics and elder mistreatment or clinical care of nursing home residents.

3.2 Focus Group Interviews with Medical Examiners and Coroners

Characteristics of the Participants. As noted above, we conducted four focus groups with a total of 40 MEs and coroners. We sought to include various types of offices. The 40 participants included eight coroners, thirty medical examiners, and two forensic pathologists from 27 States. All the MEs were physicians, and 21 reported being board certified in forensic medicine or forensic pathology. Among the coroners, two were physicians, two were emergency medical technicians (EMTs), one was a veterinarian (Doctor of Veterinary Medicine), one was a licensed funeral director, and two did not list any specific postgraduate degrees, but reported that they were college graduates. In addition to relevant education and training, the vast majority of the participants had substantial experience in their current position or their current and previous positions as MEs, coroners, or deputy or assistant MEs. As shown in Exhibit 3 below, more than half (58%) of the participants had more than 16 years experience. One of the two participants

who had less than one year of experience as an ME had relevant prior experience (3 years) as a forensic pathologist. Thus, their views are based on substantial real-world experience.

We were less successful in securing participation by MEs and coroners from small cities or towns or rural areas. As shown below, 63% of the participants were from large or medium-sized metropolitan areas. Seven of the participants (18%) were the ME for their entire state, and two other participants were the ME for a large regional group (i.e., 40 – 60) of counties. Thus, we did achieve some variation in the type and size of geographic areas served, as well as in the size of the offices.

Exhibit 3. Selected Characteristics of ME and Coroner Focus Group Participants

Location of Participant's Office	Number	Years as ME, Coroner or Deputy/Assist. ME	Number
Large metropolitan area (e.g., MSA population > one million)	12	Less than 1 year	2
Medium-sized metropolitan area (MSA population 250 – 999,999)	13	1-3 years	3
Smaller metropolitan area (e.g., population 50,000 – 249,999)	2	5 – 9 years	7
Smaller city or metropolitan area (e.g., population 5,000 – 49,999)	2	10 – 15 years	5
Small town (e.g., population < 5,000)	1	16 – 25 years	13
Largely rural/isolated county/area	1	> 25 years	10
Whole State	7		
Multiple counties	2		

There was somewhat less variation among the participants in terms of personal experience with nursing homes or nursing home residents. Thirteen of the participants (33%) reported having a family member who was or had been a resident in a nursing home, but only five of the 40 participants had ever worked in a nursing home, while two had been a physician of a nursing home resident.

The focus of our inquiry with these study participants was on four basic topics.

- First, we wanted to determine what authority coroners and medical examiners had with respect to deaths of nursing home residents.
- Second, we intended to identify coroners' and medical examiners' current practices with respect to deaths in nursing homes.

- Third, we sought to determine whether there were any barriers to investigating deaths in nursing homes and, if so, what they were.

- Fourth, we wished to determine what criteria each specialty used or would use to identify "suspicious" or "untimely" deaths in nursing homes and to select certain cases for more detailed review or autopsy.

3.2.1 Current Authority for Reviewing Nursing Home Resident Deaths

At the time of the focus group interviews, none of the participants in the 27 States represented were operating under the kind of legislative mandate that governs the Pulaski County, Arkansas Coroner's Office. However, similar legislation had been introduced in several of the state legislatures. Also, one participant reported that in his jurisdiction (a major metropolitan statistical area), a new law required nursing homes to report all deaths to the ME. The participant stated that the law, however, did not appropriate new resources for the ME's office. The result was that 2,700 deaths were reported to the MEs office in the first six months of the law; but with one investigator and no new resources, the office did not have the time to review or investigate these cases. In another jurisdiction, the ME's office was sending trained field investigators out to review all nursing home deaths and to decide whether there should be an additional review by medical personnel. In two other jurisdictions, the ME or coroner's office had an elder death review panel in their counties.

Even when they had no active review program, participants reported that the topic of abuse and neglect of nursing home residents was garnering increased attention in newspapers around the country. Thus, all of the participants were generally aware of the Arkansas legislation and of the issues surrounding forensic investigations of nursing home deaths.

Three other findings from this discussion were also noteworthy. First, some of the participants reported that they currently had the authority to review all nursing home deaths, even though they had no mandate to do so. Second, another ME reported that he/she was in the process of setting up an elder death review team. Third, many of the participants reported that they already reviewed many nursing home resident deaths, at least to some degree, because they reviewed deaths for which cremation was planned. Of course, the nature of that "review" differed, with some offices routinely sending an investigator to view all bodies slated for cremation and others conducting only a review of the cause of death listed on the death certificate then scheduling a physical viewing of the body only if there was some anomaly on the death certificate or a question raised by the funeral director.

3.2.2 Current Practice for Reviewing Deaths of Nursing Home Residents

We asked the MEs and coroners how often their offices reviewed deaths of nursing home residents and what factors generally triggered those reviews. The participants mentioned several reasons for reviewing the death of a nursing home resident. They included requests from relevant sources, suspicious causes of death, deaths without a physician in attendance, deaths in nursing homes with a prior history of elder mistreatment, and requests for cremation.

Requests and Reports. Participants reported that some of their investigations of nursing home deaths resulted from requests or reports from family members, funeral homes (e.g., the body has multiple pressure ulcers), hospitals and emergency departments, and agencies such as Adult Protective Services (APS) and the ombudsman program. In fact, there was no agreement about which type of external individual or agency generated the most reports or referrals. There were definite differences of opinion among participants about the "value" of investigations generated by such reports or requests from families. Some MEs and coroners felt that families

were a good source of potential cases of mistreatment deaths, indeed one of the only reliable sources. Other MEs and coroners argued that families were not a dependable source of reports. One reason cited by several participants was that families generally were unaware that they could request assistance from the ME or coroner's office if they suspected a mistreatment death, or as one participant said, "Families don't really know who to call." Other MEs and coroners reported that families were not always reliable in terms of reporting cases because of a lack of medical knowledge. Families may also be feeling a certain level of guilt regarding their own inattentiveness:

> We also have a fair amount of inaccurate or false reporting by relatives who have some sort of problem with the nursing home. And it frequently comes from a relative who lives out of town, is now called back at the time of death and hasn't been taking care of the person and isn't up to date on what their condition is.

Several – though not all – of the respondents felt that requests for investigation based on pressure ulcers were often problematic, regardless of the source of the report, since in their view, pressure ulcers were often unavoidable and not a sign of abuse or neglect. They also noted their difficulty in determining who was to "blame" even if they did view certain pressure ulcers as evidence of poor care. As one ME noted, "Who do you indict? The aide, the nurse, the corporation?"

Deaths Associated with Injury or Accidents. This was clearly the most common source of nursing home deaths currently investigated in most jurisdictions. The participants focused on deaths considered to be "untimely" or from "non-natural causes" and noted that such deaths were within their jurisdiction. Deaths following fractures (e.g., hip fracture) and falls with head injury were among the most common type of deaths of nursing home residents that MEs and coroners routinely investigated. The problem noted by several participants is that they were dependent on someone else to report the accident or injury and that it was related to death

of a nursing home resident. The experience of one coroner for a county that included a major MSA was fairly typical:

> In my county, we only get involved in cases if they are reported by the facility or someone else. Another way we pick up injuries in nursing homes, of course…is if they are transferred to hospitals and then the hospitals will…report them to us.

As discussed below, many of the participants felt that there were deficits in the reporting of accidents or injuries that lead to deaths of nursing home residents. This problem stems from nursing homes failing to accurately report and some physicians failing to recognize the link between an injury and a subsequent death (e.g., fall, fracture, followed by death from pneumonia) when signing a death certificate.

Another source of reports of injuries that was cited by many MEs and coroners was the State's Bureau of Vital Statistics. The staff members of these Bureaus review death certificates and forward to ME and coroner offices any cases in which the recorded cause of death involved injuries, such as falls, hip fractures, and subdural hematomas. In addition, some MEs attempted to educate staff, who reviewed the death certificates, to also report causes such as pressure ulcers and cachexia, or as one ME noted, "Those are ones that they have to be told [to report]." The problem nearly all of the participants noted was that they were dependent on reports from others, and some agreed with one ME who argued, "I suspect there's a huge number that we miss."

Deaths Associated With Potential Markers of Abuse or Neglect. A few of the MEs and coroners reported that they had conducted educational "campaigns" aimed at getting reporting of conditions they viewed as "suspicious," such as pressure ulcers and malnutrition. For example, as noted above, one ME tried to educate staff at the Bureau of Vital Statistics about potential cases of abuse or neglect. Other MEs and coroners reported attempts to educate a

variety of other types of potential reporters, including funeral directors, embalmers, APS workers, and ombudsmen.

Deaths with No Physician "In Attendance." MEs and coroners noted that they all investigated deaths that occurred without a physician in attendance. The definition of "in attendance" varied by location from no physician visit in last 14 days to no physician visit in the last 30 days. However, because of Medicare and Medicaid regulations, nearly all nursing home residents have had a physician visit within the last 30 days. Moreover, most residents' physicians routinely signed death certificates. As a result, most of the MEs and coroners reported that they seldom reviewed nursing home deaths under this authorization. Several MEs and coroners reported that the bigger problem they had with unattended deaths was in board and care homes, a topic discussed at the end of Section 3.

Cremations. Several MEs and coroners reported that they also reviewed the deaths of many nursing home residents because they reviewed all deaths in which cremation of the body was planned. As one ME noted, "[My state] has a cremation statute, where we have to investigate, we have to view, investigate and write a report…on anyone who is going to be cremated. So we pick up another 25% of the deaths that way." However, the nature of the review differed across ME and coroner offices, from actual viewing of the body by staff from the ME's office to a "paper" review. For those offices in which viewing of the body was a mandatory part of the process, the participants indicated that a set of screening criteria might be used for nursing home residents.

3.2.3 Barriers to Forensic Investigations of Nursing Home Resident Deaths

The MEs and coroners who participated in the focus groups identified a host of barriers to an increased role for their offices in forensic investigations of nursing home deaths. These can

be grouped into three broad categories barriers– attitudinal, knowledge deficits, and administrative.

3.2.3.1 Attitudinal Barriers

Some of the MEs and coroners displayed attitudes that represent significant barriers to an increased and effective role of forensic investigations to identifying and preventing elder mistreatment deaths. These barriers include the belief that elder mistreatment deaths in nursing homes are rare and ageist attitudes about the deaths of people who are ill and of advanced age. Some also felt that family reluctance might be an impediment to forensic investigation of nursing home resident deaths. In addition, some of the participants resisted the notion of using screening criteria to make forensic reviews of nursing home deaths feasible. Finally, some MEs and coroners questioned the appropriateness of forensic investigations as a mechanism for improving quality and preventing abuse and neglect in nursing homes.

Belief That Nursing Home Mistreatment Deaths Are Rare. The first attitudinal barrier was the belief held by some participants that nursing home mistreatment leading to death was rare. Since several participants felt it was not a common problem, they did not feel any particular impetus to increase the role of their offices in investigating such deaths. Several participants argued investing additional funds in conducting death investigations would yield few cases. Even though there was disagreement expressed, an exchange between participants during one of the focus group sessions illustrates this belief:

> ME-10: It's an incredibly small proportion [of deaths]. Most cases [of deaths caused by abuse or neglect] are at home.
>
> ME-4: I'm not so sure that there are such a small number…we just don't know.
>
> ME-6: Most [cases] of elder abuse or neglect probably don't occur in nursing homes. By and large nursing homes are ok. In my State, it is unlicensed homes and home situations.

> ME-4: There is an astounding lack of data on how much of a problem there is. Make it an objective to get better data…..In the 60s, nobody knew about child abuse, but now we can rattle off criteria and understand syndromes.

Ageism. The second attitudinal barrier might be classified as "ageism." Some participants felt that focusing on the deaths of nursing home residents was essentially a waste of their time and resources. Many felt that it was difficult to identify abuse and neglect, other than an explicit beating, because of the generally poor health status of most nursing home residents, and some argued that these residents would die anyway as a result of disease processes and old age. One ME stated:

> It's a difficult problem because our offices were set up for sudden and unexpected deaths. We've tiptoed or danced around this, but…if a four-year old keels over dead, that's a sudden and unexpected event, whereas when an 84-year-old keels over dead, there's a thought, true or not, "Well, what do you expect? We all gotta go sometime."

In addition, some felt that it was not the most effective use of their funds, stating that there is a greater societal payoff to addressing causes of death for children and young adults, particularly to the degree that their actions contribute to the prevention of death in these age groups. One participant explained this position as essentially a cost-benefit analysis: "Resources imply that you should focus on the young." Another participant summarized the feelings expressed by several, though not all, MEs and coroners.

> Old people die…In terms of bang for the buck, I am more concerned about children's issues. That is also the County Commissioners' calculus…..What is my job? What am I trying to do? With my resources, I don't have much interest in investigating the death of an 85-year-old woman. Most cases are quasi-neglect, and the old person declines faster than expected.

A more subtle form of ageism emerged from the discussion of some of the cases they had reviewed. For example, one participant discussed a nursing home in which there had been resident deaths from asphyxiation. The facility had done some type of cleaning to the mattresses but apparently replaced them on different beds. The result, according to the coroner was that first one and then another resident died of asphyxiation, with their heads trapped in the space left by ill-fitting mattresses and the bed rails. The coroner's response was to tell the nursing home

administrator, "After that second resident [death] that the facility had to get that mattress thing straightened out."

In addition, some participants also argued that a mandate to review nursing home deaths would detract from their ability to do what they viewed as the main or most important work of their offices. It was clear from the discussion that they did not view deaths of nursing home residents as being in the same category or as important as homicides. An exchange between three participants in one focus group illustrates this.

> ME-10: The Justice Department, city governments, they are not supporting the current process. This mandate [to review all nursing home deaths] would destroy the system.
>
> ME-9: You have lobbyists for old people, but you don't have it for homicide victims.
>
> ME-6: The President puts it in the budget for DNA testing, while murders go free because we don't have enough resources…[to investigate cases adequately and provide evidence]. Dead people don't vote…
>
> ME-9: If you had the time and money, where would you put it? Even if I had the money [for review of nursing home deaths], I would not apply it to these investigations.

Resistance to Screening. Some of the participants also resisted the idea of using a set of screening criteria that represented indicators or markers of potential abuse of neglect as causes or contributors to nursing home resident deaths. In general, those who disagreed with the use of markers argued that the frail health and advanced age of nursing home residents made each case unique and ultimately made the use of screening items or markers, such as one involving multiple Stage 3 or 4 pressure ulcers, inappropriate.

Family Reluctance. Some MEs and coroners also discussed a barrier outside of their control. They felt that it might be difficult to get family members to agree to investigations, let alone autopsies, if the genesis of the investigation was not originally a complaint by a family member. These participants also felt families might object to any delay in funeral arrangements

caused by the investigation. As one ME noted, "Families react differently. Some are outraged, and others are just relieved it is over."

Philosophical - Forensic Investigation Not the Appropriate Venue. A final attitudinal barrier related to the role of coroners and MEs in assuring high quality of care or preventing abuse in nursing homes. Many of the participants felt that it was neither an appropriate role for their offices nor an effective way to protect nursing home residents. Some felt that the money needed to implement an effective forensic review could be better spent on strengthening the existing regulatory process – although of course there was some disagreement:

> ME-11: If you think about it, the whole system is loaded wrong. Where it needs to be loaded is up front. It needs to be loaded at the point of inspection of nursing homes and regular visitations. We come at the end of the road. Somebody's dead, and they've been neglected. Now, thank you, how did that help? If anybody's going to put a federal dollar someplace, they ought to put it in someone tracking the Medicare dollar or inspecting the nursing homes or the adult homes at the front end, where it would do some good, and associate that with truly Draconian penalties.

> ME-12: The problem basically is that they will not adequately staff a state agency to inspect homes, and even if they do, the fines are low, and the reason the fines are low is that the nursing homes make huge amounts of money…and [make] huge…political donations… Going up front…if you try that, the nursing homes would get together and beat you.

In addition, some participants noted that the essential structure of forensic investigation was reactive rather than proactive, which raises questions about whether this is the most effective way to ensure quality nursing home care on a day-to-day basis. As one participant noted, "ME systems are passive systems, not proactive...If it is a quality of care issue, then that is a different issue handled by a different agency. Death investigations are probably not the way that you get good care."

3.2.3.2 Knowledge Deficits

Many participants noted that they lacked the knowledge needed to investigate nursing home deaths and that they lacked staff with the requisite knowledge to investigate cases. Most MEs and coroners did not know how to distinguish the normal course of chronic disease and

functional decline from evidence of abuse or neglect, and in general they did not have such expertise in their offices (which is why some have set up elder death review teams). As an example, one ME noted that it would even be difficult to interpret toxicology screens with expertise in geriatrics. This was also true even of injuries, with some participants clearly not viewing as suspicious falls with an unlikely prevalence in a facility or falls with an unlikely injury pattern (e.g., several reported falls causing death from head injury with no other injury, such as bruises or fractures of hip).

Participants in every focus group considered this lack of technical expertise in geriatric forensics a major issue, as the sample of comments below indicates. Moreover, they felt that deaths from neglect would be particularly difficult to identify.

- If these deaths become an issue, then we will need training to understand how to do the job.
- It's hard to get data if you don't know what to look for…What is neglect?
- I guess another barrier would be lack of knowledge…
- I think even with knowledge and all the time, it's still very difficult to decide whether there was neglect or not. I think we could take the same case and have ten forensic pathologists look at it, and you may come up with 8 or 9 or 10 different answers. I think the issue is very difficult by itself.
- But the problem I have is when I have done the autopsy, and maybe there's a certain amount or element or neglect, and while usually I haven't seen anything that I would say is active abuse, I find it very difficult to pass a judgment that this is neglect because these are patients who are extremely ill and so if they have decubitus ulcers, there are terrible decubitus ulcers, they also have every vessel in their body totally clogged and sometimes the record will say that they have been giving them the proper care, but sometimes, the still have septicemia, and they have terrible decubitus ulcers.

It is also clear from some of the cases the MEs and coroners discussed that the issue is not only lack of knowledge of geriatrics and normal aging: MEs and coroners also need knowledge about nursing home operations, the regulations that govern facilities, and what can reasonably be expected in terms of quality of care. If that were the case, MEs and coroners

would not excuse multiple deaths from asphyxiation, multiple deaths from falls and head injuries in a single facility in a two-month period, or multiple Stage 4 pressure ulcers.

3.2.3.3 Administrative Barriers

The MEs and coroners discussed three basic administrative barriers to forensic investigations of nursing home deaths. These include problems with how they get reports of potential cases, limited resources to investigate cases, and difficulties with getting prosecution of nursing home cases.

Reporting

Reliance on Death Certificates. The first problem the MEs and coroners noted was that they generally rely on death certificates. If a physician signs a death certificate and does not indicate what the ME or coroner views as a potentially problematic cause of death, there is usually no forensic investigation. As several participants noted, resource constraints essentially necessitate acceptance of a physician-signed death certificate. One ME stated, "I don't think we pick those up those where the doctor signs the death certificates. That really ends the inquiry, unless, perhaps, the funeral director would see something." Another ME elaborated on this:

> We rely totally on death certificates…We approve all of those, but we don't see the bodies. And we rely on the cause of death that is on the death certificate, so I mean, I'd like to believe that what the physicians write on there is some semblance of what is actually going on. But occasionally…we come across a case where we do request the medical records…and the story is so far from what is actually on the death certificate. But we have no way of reviewing every single death certificate.

Concern about the Accuracy of Physician Reports on Death Certificates. Some participants felt that the way death certificates were handled by physicians was a barrier to correct identification of some potential mistreatment deaths. They argued that physicians routinely sign death certificates but do not have training in forensics. As a result, they don't necessarily think about or identify "root causes" of the deaths. For example, a physician reports

the resident died from pneumonia but does not connect it with a fall that caused a fracture, immobility, and ultimately the pneumonia. They also noted that many physicians who sign death certificates not only lack knowledge of forensics, they also lack knowledge of geriatrics and thus may view as "natural" some problems and conditions of frail elderly nursing home residents that may in fact indicate mistreatment:

> ME-12: A lot of doctors really think that if you come in with all these terrible injuries, you know, contractures, dehydrated, decubitus ulcers, so what's wrong?
>
> ME-11: They think that's the natural history.
>
> ME-12: They think that's natural, and they sign it [the death certificate].
>
> ME-11: It's worse than that. The forensic scientists think it's a natural death, too.

Some MEs and Coroners also reported that some physicians, particularly those who are strongly affiliated with a particular nursing home, might deliberately falsify the cause of death:

> ME-34: There is one nursing home where they physician refuses to notify us [about injuries leading to death]. Even if he knows it's a subdural, he will put something else. So if he does put something else that's a natural cause, no one's going to catch that.
>
> ME-40: So, how would a case like that get caught…?
>
> ME-34: The nurse called the investigator.

Many of the MEs and coroners also reported that they did not trust reports from many nursing homes and that it would not be realistic to rely on them to report mistreatment deaths. Moreover, some participants felt that nursing homes misled physicians, which also contributed to unreliability of death certificates.

> ME-12: Nursing homes uniformly lie to MEs. Our experience has been, like in asphyxia deaths, they'll just pick them up from wherever they are hanging [from restraints], put them in the bed, and dress them nicely, put the covers up to below their neck, and then call the doctor and say, "He's passed away." And if the doctor even shows up, he's presented with the body, just lying there in bed in pajamas and everything and "Oh, okay, he's dead," and they just sign the death certificate.
>
> ME-18: Nursing homes are not reliable informers. I had one where…[nursing home staff] took them out of a bathtub where they drowned and put them in bed.

MEs and coroners also noted that nursing home records could be falsified, which makes investigation of nursing home deaths more difficult. As one ME noted, "Stage 3 or 4 [pressure ulcers] is our screener. They are investigated. It is neglect. But, nursing home records are fabricated. Nursing notes vary from minimum to inadequate."

As discussed below, the geriatricians, many of whom had been medical directors in nursing homes, also attested to the unreliability of medical records in some nursing homes, particularly those with quality of care problems.

Inadequate Resources

One issue on which there appeared to be universal agreement was that their offices currently had inadequate resources to review all nursing home deaths. MEs and coroners estimated that a mandate or legislation such as that in Arkansas would dramatically increase their workload and that their resources were inadequate to meet the demands of more intensive reviews. The following quotes from participants illustrate the broad consensus on these issues.

- The caseload would increase 100% in metro areas.
- Current funding does not support the current process. This mandate [to review all nursing home deaths] would destroy the system.
- It would be more work…where we don't have the funds to do core functions.
- The reason we're deficient is not because [nursing home deaths] are not being reported but that we can't send someone to see what's really going on. I mean, we don't have any investigators. We're talking money…..It would double our cases…but the bulk of the cases are going to be inspections, inspections you could use nurse investigators.
- We can create lists [of markers for mistreatment], but the resources for screening are not available.

Difficulty Getting Prosecutions

MEs and coroners noted that even if they were able to overcome the problems of reporting and scarce resources, many faced significant difficulty in getting local prosecutors to follow through with prosecutions. They identified three core reasons for lack of prosecutions:

lack of knowledge, ageist attitudes, and concerns that the standard of proof in criminal cases makes successful prosecution difficult in cases of nursing home deaths.

First, MEs and coroners noted that many prosecutors did not understand the nature of abuse and neglect as it applies to nursing home residents. First, prosecutors often did not view premature death of persons with multiple chronic diseases as necessarily a significant or easily "provable" crime. Second, the participants argued that prosecutors did not necessarily know how to present such cases. Third, MEs and coroners noted the difficulty of determining whom to charge, even if cases of abuse or neglect are identified. As one participant noted, there might be 20 or 30 people involved in the care of a resident, from CNAs on multiple shifts, nurses, dietary aides, and therapists, to the director of nursing (DON), the administrator, and, ultimately, the owner. All of these factors make such cases unattractive to many, if not most, prosecutors. One conversation demonstrates this attitude:

> ME-11: I'll tell you what would do it is a couple of good court cases where nursing home owners spend a little time in jail...the state pen with all the junkies and perverts. I assure you some of these white collars would change their style. But we can't get prosecutors to do anything about it even when we find it.
>
> ME-18: Because they don't understand it.
>
> ME-12: They don't understand it.
>
> ME-17: Well, the big thing that comes up as far as prosecution and malpractice…what are the damages? You've got an 85-year-old person who dies, and what's the damage?
>
> ME-15: Even if they [report suspected abuse or neglect], you're still left with the quandary that you have these old people with a myriad of potentially lethal diseases on top of whatever. If they've got overt neglect, dehydration, those things you could pick up if you got to *look* at them. But you know, it's hard to discount the contribution of all their natural diseases as well. I think that's sort of the underlying problem that people have a hard time dealing with this or accepting this as a legitimate problem, particularly from a prosecutorial standpoint. They had all this disease that they were going to die from anyway, so why worry about this?

A second problem some MEs and coroners identified was ageist attitudes among some prosecutors. Essentially, they had a different standard for crimes against frail elderly nursing

home residents than they applied to cases involving children. One case discussed by a participant that involved rape of a resident with dementia illustrates this double standard.

> And then, while I was there investigating [another case], a nurses' aide pulled me aside and said, 'You know, there's another woman that's repetitively being raped by another [resident]…' He was younger…like 30…year-old guy who was in the…home because of a psychiatric…problem. And I referred it to the attorney general's office because it was just so appalling, and they really found no basis for an investigation and said it wasn't prosecutable because the woman being raped had an IQ of a four-year-old. So they couldn't identify that it was consensual and the person doing it also had a psychiatric condition….

Another participant in this focus group responded with a telling question:

> Can I ask you a question, if they raped a four-year old, wouldn't they do something? Wouldn't that be considered non-consensual? It should probably be diminished capacity [for the perpetrator].

However, a third participant noted that the attorney general's office might have viewed this case as one not to prosecute not only because of the characteristics of the demented female resident who was raped but also because of the nature of the rapist, stating, "But probably [prosecuting] the perpetrator was a waste of time. What are you going to do?...You just return him to his room." This case suggests that the AG's staff held the well-being and rights of the female residents in the facility in fairly low regard. First, they did not prosecute the rape, as they probably would have if the victim had been a child. Indeed, other research by Ann Burgess at the University of Pennsylvania has found that rapes in nursing homes are not as uncommon as one might expect but there are seldom prosecutions.(11) Second, the AG's office apparently did nothing to remove a known rapist from a setting in which he had access to vulnerable elderly women.

A third disincentive for prosecutors to accept and pursue cases involving the death of a nursing home resident relates to the standard of proof called for in criminal cases. Such cases call for proof beyond a reasonable doubt. As one forensic pathologist noted, when asked in court whether it was *possible* that the resident's decline and death could have been caused by her

underlying diseases, the pathologist had said that in her/his opinion, it was possible. As other MEs noted:

> ME-8: Yeah, from a prosecutorial standpoint, they're held to the standard of beyond a reasonable doubt, and with an older person, it's probably easier to establish a reasonable doubt.
>
> ME-11: Prosecutors are happy when you have bruises and fractures. Prosecutors are not happy when people get the dwindles and die. (33)

The fact that prosecutors were often unwilling or felt unable to pursue cases of nursing home death, even if well-investigated by an ME or coroner's office, made some participants understandably unwilling to devote significant time, energy or resources to such cases.

3.3 Focus Group Interviews with Geriatricians

Two focus groups were held with a purposively selected and recruited group of geriatricians during the 2003 annual meeting of the American Geriatrics Society. Fifteen geriatricians from 11 States participated, most from large metropolitan areas. Among the 15 participants, twelve were board certified in Geriatric Medicine, and all but two had experience in either forensic geriatrics or working with nursing home residents (i.e., as medical director of a nursing home or physician for nursing home residents or both). Five had a family member who was or had been a resident in a nursing home.

The participants' discussion during the focus group interviews concentrated on markers or indicators of potential elder abuse or neglect in nursing homes. This is discussed in the next section. However, other issues were raised that are worth noting.

First, geriatricians were uncomfortable with use of the phrase "abuse." This connoted malpractice to them and made them less willing to report potential cases of abuse. They preferred the phrase "mistreatment."

Second, some participants viewed nursing home records with a jaundiced eye, reporting that they were often inaccurate, particularly records that, in theory, recorded care provided to a resident on something like a checklist or flow chart (e.g., resident received turning and positioning every two hours; amount of food the resident consumed during a meal; range of motion exercises performed).

Third, some participants admitted being unwilling or at least reluctant to report suspected cases of abuse or neglect, since they regarded the remedies associated with such reports as not being worthwhile in terms of helping or forcing the nursing home to improve its performance. One such participant noted that if all states had a system like Washington State's of providing technical assistance to facilities with Master's-trained nurses experienced in geriatric nursing, he would report everything – since he viewed this system as one capable of providing a useful response to such reports.

Fourth, some of the participants noted that much of neglect and possibly some abuse were attributable to low staffing and poor training of staff in nursing homes – a cause not easily addressed by reporting cases or even by investigations of cases by ME and coroner's offices, at least in their view.

Fifth, some of the geriatricians noted that it was difficult to identify cases of elder mistreatment that led to death – at least in their view, particularly if they viewed "intention to harm" as a necessary part of the definition of abuse or neglect. As one argued:

> Intentional or unintentional? A good example is, a CNA wheels the patient by wheelchair, transfers the patient from the patient's room to the dining room. But…the patient put pressure on her arms and feet [and] fell from the wheelchair…She did not have a seat belt on. Is this abuse? There's no intention to harm the patient. So there we have to differentiate. The other thing is elderly patients' skin becomes so thin….Bruising is very common without really hitting a person. It can happen with the rail on the bed or whatever. But family comes in [the] next morning. "My mom has a bruise on her arm." We have to investigate …we really have to do our best to prevent neglect and at the same time, we have to listen to the other side, what's the CNA doing?

Sixth, many of the geriatricians were skeptical about the efficacy of using forensic investigations to improve quality or even to prevent mistreatment. As one geriatrician noted, many cases of abuse and neglect do not lead to death:

> How many episodes of neglect or abuse… end up in death? You know, because what you're talking about is your using screening as…or do the episodes result in immediate death? So certainly, abuse or neglect that results in hip fracture, which causes a death six months from now…the death is related…But the problem is investigating [six months or a year]…later. Death as a screening is the wrong way to do it. You need it [investigations] around [the time of] these episodes and I'm thinking that a lot of these don't result in death or they result in death down the way…

3.4 Screening: Potential Indicators of Elder Mistreatment

From discussions with Mark Malcolm and others, it was clear that a working system of forensic review of nursing home deaths would require, at a minimum, a set of screening criteria to identify cases that, based on an initial review, would be referred on for further investigation and possibly autopsy. Thus, one of the main goals of the focus groups was to discover what MEs, coroners and geriatricians regarded as screening criteria or potential markers of elder mistreatment.

Participants were asked to discuss what they believe to be markers for mistreatment within long-term care facilities. Analysis revealed that the markers identified could be categorized as individual markers or facility-level markers. There were differences expressed between the groups. Geriatricians, as would be expected, focused more than MEs and coroners upon markers of abuse or neglect for living residents (e.g., observed behavioral changes). In addition, MEs and coroners tended to focus on deaths associated with "accidents" (e.g., fall with fracture followed by death) as opposed to cases of neglect. There was disagreement about how certain medical diagnoses should be interpreted. For instance, the geriatricians argued that malnutrition does not necessarily mean mistreatment, pointing out that a resident, who has an advanced directive and is receiving palliative/comfort care only, might not be receiving nutrition

or hydration at the end of life and will thus be malnourished and dehydrated at death. Similarly, some disease processes (e.g., end-stage cancer) may be associated with profound weight loss. Thus, they warned that such markers are not automatic indicators of abuse or neglect and will need further investigation. It is also interesting to note that MEs, coroners and geriatricians all discussed a focus on characteristics of facilities rather than individual residents. One ME argued that you needed to focus on facilities with a history of elder mistreatment deaths, what he referred to as an "index" case. One ME stated, "Find index cases, and then look at all deaths from that facility...How do you get the index case? Luck. A nurse reports or a family member." Similarly, one of the geriatricians argued that he would focus his efforts on the worst 10% of facilities in the relevant geographic area (e.g., State or county). He argued that the "pick up" rate of positive cases was likely to be better in such facilities, providing they were correctly identified. These markers are summarized in Exhibit 4 below.

Exhibit 4: Markers for Mistreatment
Individual Resident Markers • Behavioral changes (e.g., more quiet or withdrawn) • Unexplained weight loss • Malnutrition • Dehydration • Bruising in unusual places (e.g., inner thigh, neck, frontal trunk, head, face) • Uncommon fractures • Fall with injury (fracture, subdural hematoma) • Injuries that are inconsistent with the medical/health history • Inconsistency in what you are told by staff and what you actually see • Delays in treatment for injury • Pressure ulcers (usually Stage 3 or Stage 4) • Sepsis • Insects (e.g., maggots) • Contractures • Recurring injuries • Very poor hygiene (e.g., resident is covered with filth)
Facility Level Markers And Practices • Clusters of problems or patterns within institutions (e.g., a disproportionate number of residents with weight loss, multiple residents not getting medication) • General inconsistencies in charting, especially regarding weight and food intake • Poor condition of a facility (i.e., smell, lack of cleanliness) • Historically poor performing nursing home • Facility with a prior case of elder mistreatment death

3.5 Implications and Recommendations

Finally, participants were asked what would help in making this system more workable, and even when not asked, most volunteered suggestions for how to make forensic investigations of nursing home deaths more effective. First, the MEs and coroners recommended enhanced education about elder mistreatment and reporting. They suggested educational efforts for ME and coroner offices and for potential reporters, including family members, funeral directors, hospitals, APS workers (where relevant), and ombudsmen:

> To me, the biggest item is reporting, and the reporting can only come from three places, the nursing home, the family or the funeral director. We don't feel that nursing homes are entirely believable, and to get to the other two…you'd have to do education…about what [families'] rights are…and where they could report.

Some MEs and coroners also noted that education was needed for agencies involved in investigations (e.g., police, ME/Coroner's office investigators) and prosecutions. Several MEs and coroners suggested using Medicare dollars for many of the activities associated with enhanced forensic investigations of nursing home deaths. And although they did not specifically mention this, the Medicare-funded Quality Improvement Organizations are a potential source of geriatric expertise and training.

> Coroner-7: If these deaths become an issue, then we will need training to understand how to do this job. This will especially be a problem for non-physicians. It's a major issue to get people educated. Let Medicare pay for it.

> ME-11: At the same time, you have to educate the judges, you have to educate the prosecutors, and you have to educate the policemen.

Second, some participants recommended the development and use of elder death review teams in order to have multidisciplinary teams who are familiar with geriatrics and with what nursing homes are supposed to do.

Third, some participants suggested that preventing abuse and neglect, as well as identifying it when it occurs "has to be a joint effort" with ombudsmen and survey agencies. Several participants felt strongly that the role of the survey agencies needed to be strengthened, and one indicated he had worked with the survey agency to help it improve the investigative skills of its staff. "Our nurse investigator was going through records and saw discrepancies…They called in the survey agency and did some joint investigations and helped them figure out things to look for."

Fourth, some participants felt state or federal legislation was needed to improve the reliability and validity of death certificates.

Fifth, in addition to noting the need for additional resources, several participants recommended studies to identify the number of new cases they would encounter and the number that would need further review, as well as the expected rate of identifying elder mistreatment deaths. This would help them recognize the seriousness of the problem and estimate the level of additional resources needed.

Sixth, several of the MEs and coroners argued that any increased role of MEs and coroners in reviewing deaths in nursing homes should be extended to personal care homes. The quotes from various participants illustrate the consensus about this issue:

- In my state, the issue is unlicensed homes, personal care homes.
- Include adult care homes in anything that you do.
- The adult personal care is a whole different world, and it's the one, in my opinion, that needs the most change. Another reason that's so is the folks there are the ones that are disconnected. They have no kin, no one's keeping track of them, that's why they're in adult care to begin with…And they stay in these adult care facilities until…they stay there period, no matter what their condition becomes…They just stay there until they go to God. And there's no one there responsible…because your not dealing with nurses, not even…LPNs…[or] nursing assistants.
- I guess the different places I've worked, that's the most horrendous cases; the most appalling things come out of those adult care places.
- They are worse than nursing homes. I just recently had a case where a woman walked away from …[the board and care home], and one of the nurses' aides saw her walking away. She was an Alzheimer's patient…And she [the aide] just let her walk away. She [the resident] froze to death.

Ultimately, one ME argued that elder mistreatment will be recognized as a social problem in the same way that child abuse was:

> Well, I think the whole business of elder abuse is just going to follow the same progression as child death and child fatality…which was first a recognition of the problem, and…second, the big education campaign, and then three, finally, the feds loosened up some dollar bills…When that money states coming down, people start paying more attention to it.

3.6 Summary

The participants in these focus groups, in general, found that barriers exist at many levels in terms of attempting to locate cases of mistreatment within LTC facilities. For the geriatricians, the problem begins with defining mistreatment and knowing exactly who is responsible for the mistreatment (e.g., employee, the administrators, the entire facility). For coroners and MEs, it involves jurisdictional issues or finding the cases. Once cases are found that may involve mistreatment, determining a course of action is not always clear, and unfortunately, some of the participants expressed a lack of concern about these issues.

However, solutions to these problems were offered by both groups, including education about elder mistreatment, formation of elder abuse review teams, improvements in data collection, and better communication between the professional groups involved with LTC. When comparing these focus group comments with the interviews with Mark Malcolm and his staff, some of the problems that these focus group participants cited are non-issues for PC. For the PC staff, they have the legal jurisdiction to conduct death investigations. Problematic records and inconsistencies are not tolerated. Families, in general, have not reacted negatively to the presence of the coroner. The focus groups discussed real problems facing those who may deal with LTC mistreatment, and the PC interviews suggested some methods to address these problems.

4. Analysis of Death Investigation Records

4.1 Design and Methods

The third phase of this project involved a review of nursing home death investigations from Pulaski County, Arkansas in 2001. Investigation records from that year were obtained from the Pulaski County Coroner's office. An in-depth record review of the investigation records was completed. Demographic information, facility characteristics, and investigation findings are included in death investigations records. This information was abstracted and entered into an Excel database. Suspicion of mistreatment was determined by coroner referral to the attorney general and/or medical examiner. SPSS software was used for statistical comparisons between referrals and non-referrals. In addition to this, we identified cases with suspected abuse and/or neglect and recorded details that led to such suspicion.

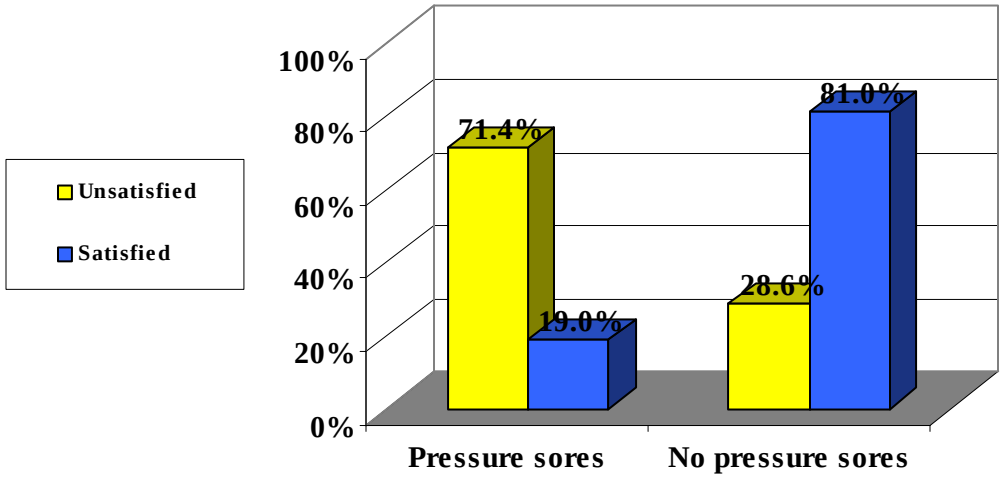
4.2 Results

There were 533 nursing home deaths in Pulaski County, Arkansas in 2001. Of those 533 deaths, 92.9% (495) had on-site investigations. The decedents were primarily white and female (82.8% and 67.1% of the 495 investigations, respectively). The average age was 84.4 years. In 31.7% of the cases (156), coroners spoke to family members. Ninety-one percent (142) indicated that they were satisfied with the care the decedent received, 8.3% (13) said they were unsatisfied, and one family member specifically requested an autopsy. Female family members were more likely to be dissatisfied with the care received (women, 16.2% dissatisfied; men, 0.0% dissatisfied; $p<.01$).

In 24.2% of the cases (119), pressure sores were noted by the coroner, although pressure sores were listed in only five cases as a diagnosis found during review of the medical records.

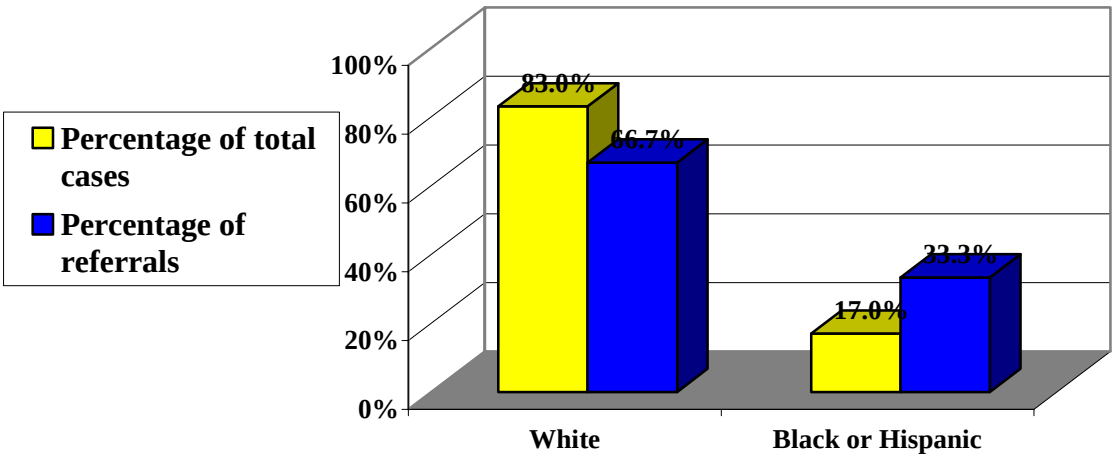
Among those 119 decedents, 26.1% (31) had three or more pressure sores present. The most frequently occurring location for pressure sores was on the coccyx/sacral area (23.6%) followed by the foot/toe (18.5%) and the rest of the lower extremity (13.4%). 21.6% of white decedents had pressure sores versus 37.3% of black or Hispanic decedents (p<.01). Pressure sores were present in 71.4% of cases where family members were dissatisfied with care, but they were present in only 19.0% of cases where family members were satisfied (p<.001, Exhibit 5).

Exhibit 5:Family Satisfaction vs. Presence of Pressure Sores



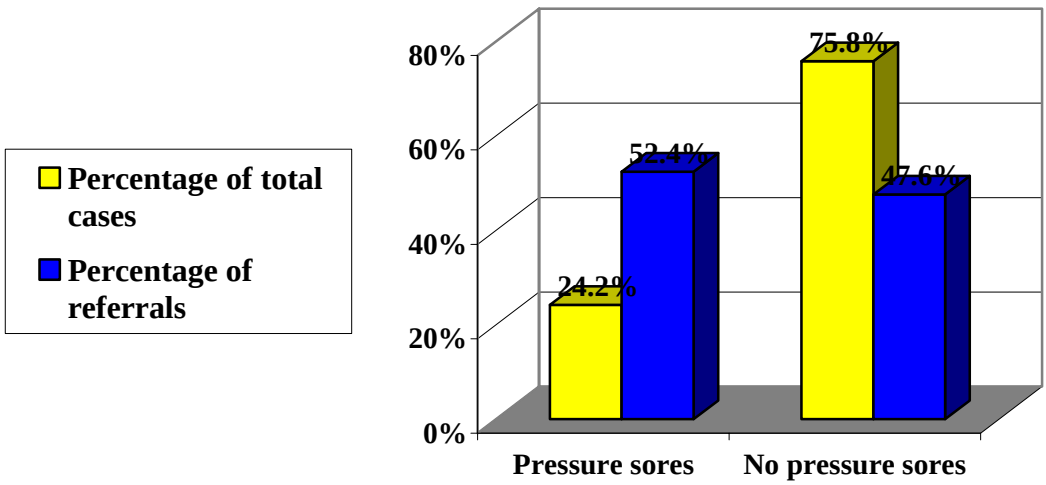
Twenty-one cases (4.2%) were sent to the Arkansas Attorney General's office for further investigation of mistreatment. Fifty percent of cases where family members were dissatisfied were sent to the Attorney General versus 1.4% where family members were satisfied (p<.001). Although only 17.0% of the total cases were Black or Hispanic, 33.3% of the cases sent to the Attorney General were Black or Hispanic (p<.05, Exhibit 6).

Exhibit 6: Referred Cases vs. Race/Ethnicity



One clinical factor associated with referrals to the Attorney General was the presence of pressure sores. Although only 24.2% of the total cases had pressure sores present, 52.4% of the cases sent to the Attorney General had pressure sores ($p<.01$, Exhibit 7).

Exhibit 7: Referred Cases vs. Pressure Sores



Another factor associated with referrals was the receipt of hospice care in the facility. Cases sent to the Attorney General were three times more likely to have received hospice care than cases not sent; 9.8% of those referred received hospice care, whereas 3.2% of those not referred received hospice care ($p<.05$). One final factor associated with referrals was dissatisfaction of family members with the care received. Cases where decedents' family members were unsatisfied were more likely to be sent to the Attorney General; 50% of those unsatisfied were sent and 1.4% of those satisfied were sent ($p<.001$).

Details of cases actually referred to the Attorney General included the following:

- Fall from wheelchair, multiple spinal compression fractures, autopsy revealed myocardial infarction, probably no abuse.
- Multiple large stage IV pressure ulcers that began and worsened over a 2-month period with little documentation for plan; admitted to hospital and original nursing home then refused readmission.
- Fatal burns suffered while trying to light restraint straps on fire with butane lighter.
- Respiratory failure after hospice nurse administered a narcotic patch without doctor's orders. Body exhumed to settle case.

4.3 Linkage with the Minimum Data Set

This project also included a pilot attempt at linking these decedents to their nursing facility's Minimum Data Set (MDS) in order to locate resident and/or facility-level factors that may indicate higher risks of mistreatment. First, all Arkansas nursing home MDS assessment records dated on or prior to December 31, 2001 were extracted from a copy of the national MDS database maintained by the Center for Health Systems Research & Analysis (CHSRA). A list of all combinations of resident ID and facility ID for assessments dated from July 1, 2000 through December 31, 2001 was compiled from the full Arkansas MDS extract. Next, 13 different combinations of decedent name (first and last), sex, date of birth, date of death, and facility name

from the investigation record were constructed to serve as possible linkage keys to similar combinations available from the MDS records. We found that the use of the nursing facility name was complicated by the lack of a facility identifier code common to the investigation records and the MDS records. While the MDS re-codes contain several facility ID codes (Medicare ID, Medicaid ID, etc.), the investigation records only provide the name of the facility. A partial mapping of investigation facility names to MDS facility names was performed based on resident records with an exact match on last name and DOB. Of the 533 death records, 317 provided a unique match on both of these variables. A cross-tabulation of these 317 records by investigation facility name versus matching MDS facility name provided a tentative crosswalk between investigation and MDS facility names.

Of the 37 facilities on the investigation listing, 23 mapped to a single MDS facility name. Six other facilities mapped to more than one MDS facility name, but it was clear which MDS facility was the correct match based on similarity in name, number of matching residents or conflicts with other facility mappings. These multiple matches may be due to resident movement among facilities over the course of the MDS extract period. Four facilities from the investigation records had a few resident matches, but no clear correspondence to a specific MDS facility. Some LTC facilities do not submit MDS assessment records (e.g., intermediate or assisted living facilities, hospice facilities). Any resident record matches for these facilities are probably attributable to prior stays at MDS-submitting facilities within the MDS extract timeframe. Finally, four facilities had no unique resident matches. However, subsequent analysis of three of these resident records allowed us to identify the matching MDS facility name. Of the 533 death records, 458 produced a unique match on at least one of the 13 variable combinations, while 75 produced ambiguous matches or no matches with the MDS facility/resident listing. All but one

of the deaths referred were uniquely linked to MDS records. The matching status of each of the 533 death records is summarized in the Exhibit 8 below.

Exhibit 8: Initial MDS Matching Status of Investigation Records

Status	Not Investigated	Investigated	Referrals	Total
Unique Match	30	428	20	458
Ambiguous Match	2	8	0	10
No Match	6	59	1	65
Total	38	495	21	533

It was necessary to assess the strength of the unique matches, since a unique match might only be based on a matching last name, with no other matching variables. Strength of match was classified as certain, probable, possible and unlikely for each of the 458 records with unique MDS matches. These classifications were determined by which key variables (first name, last name, sex, DOB, DOD and facility ID) matched. The Exhibit 9 summarizes the classification logic used in this analysis.

Exhibit 9: Strength of Match Classification Logic

F. Name	L. Name	Sex	DOB	DOD	Facility	Strength
x	x	x	x	x	x	1 - certain
x	x	x	x	x		1 - certain
x	x	x	x		x	1 - certain
x	x	x	x			1 - certain
x	x	x		x	x	1 - certain
x	x	x		x		1 - certain
	x	x	x	x	x	1 - certain
	x	x	x	x		1 - certain
x	x	x			x	2 - probable
x	x		x	x	x	2 - probable
x		x	x	x	x	2 - probable
	x	x	x		x	2 - probable
	x	x	x			2 - probable
	x	x		x	x	2 - probable
x	x	x				3 - possible
x	x		x		x	3 - possible
x		x	x		x	3 - possible
x		x	x			3 - possible
	x	x		x		3 - possible
		x	x	x	x	3 - possible
x	x					4 - unlikely
	x	x			x	4 - unlikely
	x	x				4 - unlikely
	x				x	4 - unlikely
	x					4 - unlikely
		x	x			4 - unlikely

Applying this logic to the 533 investigation records, we obtained the results shown below in Exhibit 10.

Exhibit 10: MDS Strength of Match

Status	Not Investigated	Investigated	Referral	Total
Certain	21	363	18	384
Probable	2	33	2	35
Possible	3	16	0	19
Unlikely	4	16	0	20
No Match	8	67	1	75
Total	38	495	21	533

So, there are 419 certain/probable matches among the 533 death records in the investigation spreadsheet file. Twenty of the 21 deaths referred can be matched to MDS records, leaving 399 non-referral matches. Next, comparison groups were formed based upon the strength of the MDS match and the prior classification of the most recent MDS record. “Listed Referrals” are those

investigation records with a certain or probable MDS match which were referred to the Attorney General (n=20). "Listed Non-Referrals" are those investigation records with a certain or probable MDS match which were not referred to the Attorney General (n=399).

The following table highlights those MDS items that exhibited at least a moderately significant statistical difference ($p \leq .15$) between the Referrals and the Non-Referrals. "Referral Deaths vs. Non-Referral Deaths p-value" tests the assumption that the MDS item value distribution is the same for the "Referral Deaths" and the "Non-Referrals Deaths". Small p-values indicate that the assumption of equality is unlikely. For instance, decedents referred were more likely to exhibit a resistance to care which is not easily altered (p=.112); a more limited range of motion in legs (p=.029) and feet (p=98); and a greater prevalence of Stage 3 pressure sores (p=.00). Exhibit 11 summarizes all significantly different ($p \leq .15$) MDS items.

Exhibit 11: MDS Item Summary by Comparison Group (Significant Differences Between Referrals and Non-Referrals)

MDS Item	Value	Listed Referrals	Listed Non-Referrals	Ref. vs. Non-Ref. p-value
Count		20	375	
B4 - Cog. Skills	Independent	25.0	9.1	
	Mod. Ind.	20.0	15.5	
	Mod. Impaired	20.0	34.7	
	Sev. Impaired	35.0	39.2	9.7%
B5A - Easily Distracted	OK	75.0	77.1	
	Present, not recent	20.0	21.3	
	Present, recent onset	5.0		0.0%
E4BB - Verbally Abusive – Alterability	Not present or easily altered	80.0	91.2	
	Present, not easily altered	20.0	7.2	4.1%
E4CB - Physically Abusive – Alterability	Not present or easily altered	85.0	93.9	
	Present, not easily altered	15.0	4.5	4.0%
E4EB - Resists Care – Alterability	Not present or easily altered	70.0	82.1	
	Present, not easily altered	30.0	16.0	11.2%
G2A – Bathing	Independent		1.1	
	Supervision		1.1	

MDS Item	Value	Listed Referrals	Listed Non-Referrals	Ref. vs. Non-Ref. p-value
	Physical Help Transfer	20.0	5.1	
	Physical Help Bathing	25.0	32.5	
	Total Dependence	55.0	60.0	
	Activity Not Occur		0.3	14.7%
G4DA - Leg ROM	No limitation	40.0	59.7	
	Limited on one side	15.0	20.3	
	Limited on both sides	45.0	20.0	2.9%
G4EA - Foot ROM	No limitation	65.0	72.0	
	Limited on one side	5.0	14.1	
	Limited on both sides	30.0	13.9	9.8%
G6B - Uses Bedrails	No	65.0	45.9	
	Yes	35.0	54.1	9.5%
H1B - Bladder Incontinence	Continent	50.0	31.5	
	Usually continent		5.3	
	Usually incontinent	10.0	3.5	
	Frequently incontinent	15.0	10.4	
	Incontinent	25.0	49.3	9.4%
H3D - Indwelling Catheter	No	65.0	80.3	
	Yes	35.0	19.7	9.9%
H3I – Ostomy	No	90.0	96.5	
	Yes	10.0	3.5	13.6%
J5A - Status Unstable	No	75.0	56.8	
	Yes	25.0	43.2	10.8%
J5C - End-Stage Disease	No	75.0	91.7	
	Yes	25.0	8.3	1.1%
M1C - Stage 3 Ulcer	Mean	0.60	0.07	
	Std. Dev.	1.98	0.37	
	Std. Dev. of Mean	0.44	0.02	0.0%
N1B - Awake in Afternoon	No	10.0	28.3	
	Yes	90.0	71.7	7.4%
N1C - Awake in Evening	No	35.0	67.7	
	Yes	65.0	32.3	0.3%

Note, however, that among 119 available MDS items, it is expected that 15%, or 18, would generate a p-value of 15% or less, even if there is no difference in the MDS behavior between the Listed AG Deaths and the Listed Non-AG Deaths. In other words, this list may be largely random. To obtain a more comprehensive assessment of the difference in MDS behavior between the AG and Non-AG deaths, we constructed a combined statistical test of the differences across all 119 MDS items. The null hypothesis of this test was that the distributions

of all 119 MDS items are the same for both groups of deaths. The resulting test statistic produced a p-value of .10. This implies, under the null hypothesis, that the observed differences in MDS values would occur one in ten times or less. So, while there is some indication of a difference, the indication is not dramatic. A larger sample is needed to determine more precisely the magnitude of the overall difference in MDS values and to reliably identify the MDS items that differ between AG and Non-AG deaths.

4.4 Summary

This analysis of the investigation records is a one year cross section of a process that has been ongoing for over five years. Several factors were suggested to be associated with referrals to the Attorney General and the Office of Long-Term Care for suspicion of mistreatment. The presence of pressure sores, family dissatisfaction, hospice care, and minority status were some of these factors, although they may not be independent of each other. Multivariate analysis with a larger sample will be necessary to determine independent risk factors. A continuation project is planned to abstract all of the PC nursing home death investigation records from July 1, 1999 to December 31, 2004. All cases referred for further investigation due to suspicion of mistreatment will be identified. As with the database created from 2001 data, the new database will be used to further clarify what factors cause investigators to consider a nursing home death suspicious for mistreatment. Expanding the database to include 1999-2004 will increase the number of referrals over fourfold.

Linkage with the MDS was a first attempt at locating resident and/or facility-level factors that may indicate higher likelihood for mistreatment. In the continuation project, quality indicators from the MDS of Pulaski County nursing homes will be analyzed longitudinally. The most recent MDS discharge record, along with the most recent MDS quarterly or full assessment,

will be matched to our death investigation database using the process described above. The MDS analysis will help determine whether there are any commonly assessed resident or facility characteristics that help separate suspicious resident deaths from other deaths. More precise resident identifiers (such as the social security number) and facility identifiers (such as the facility's Medicare number or state-assigned MDS number) will be sought to simplify and improve the linkage between the MDS and death investigation records.

Data from the Online Survey, Certification and Reporting (OSCAR) will also be used to assist in the identification of markers for mistreatment. The OSCAR data network is a compilation of data for the purpose of Medicare and Medicaid program certification, collected during the facilities' state inspection surveys, which must occur at least every 15 months. The database includes nursing home operational characteristics, aggregate resident characteristics and health deficiencies for each facility. OSCAR data may offer a different set of facility characteristics to complement the MDS findings.

The continuation project will also allow a comparison of quality indicators in Pulaski County to those in other Arkansas counties where the law may not be as strongly enforced. MDS and OSCAR data may suggest quality improvements in Pulaski County over time that did not occur in these other counties. This would support the statements made by the PC investigators that quality has generally improved in their county as a result of the law's enforcement.

5. Overall Discussion and Future Directions

The three phases of this project provided us with distinct types of information. The focus groups garnered general qualitative information concerning forensic investigations of institutional deaths in the United States. The interviews also offered qualitative information about forensic investigational procedures, from a team with extensive experience in LTC death investigations and a political mandate to conduct such investigations. Finally, the database analysis provided a snapshot of one year for a process that has been ongoing for over five years, as well as generating information about what factors may lead to referrals to the Attorney General.

Although there was some overlap from each phase in terms of what may constitute markers for mistreatment (e.g., pressure sores, family dissatisfaction), the focus groups generated a different impression of the potential impact of forensic science in LTC deaths. Barriers (at many levels) were emphasized during the focus groups; however, during the interviews with Mark Malcolm and his staff, it became apparent that certain barriers (e.g., staffing, funding, awareness) had not been significant barriers in PC. Other barriers expressed during the focus groups, such as a belief that autopsies are not useful for death investigations and a general sense of ageism, were not expressed during the PC interviews.

Based upon the findings of this study, we are conducting a continuation project with three distinct aims. Within all three phases of the current project, markers for mistreatment were suggested. Some of these markers (e.g., pressure sores, malnutrition) are documented in research on nursing home mistreatment (17,34,35). However, within all three phases, other markers were suggested that have not been offered as signs of mistreatment. Particular knowledge or impressions about what may constitute elder mistreatment differ between disciplines and

occupations. These disciplinary boundaries can generate disagreement over what mistreatment actually is. Given this, the first aim is the further elucidation of markers for elder mistreatment, with the intention of broadening the definition and bridging disciplinary and occupational gaps.

Next, as was discussed, during the interviews, respondents indicated that they believe that the investigations have both identified instances of mistreatment and improved the quality of care within PC nursing homes. Based on this, the second aim is to determine if the Long-Term Care Reporting Law in Arkansas has actually made a difference in quality of care in Pulaski County, as was suggested within the interviews. This will allow us to understand if and how PC may be different from other Arkansas counties.

The third aim is linked to the first two aims. By developing a better understanding of markers for elder mistreatment within institutions of long-term care, and investigating the effectiveness of the Long-Term Care Reporting Law in terms of quality of care improvement, the next step is to assist more coroners in conducting investigations. Specifically, the third aim is the development of an adaptive investigative model for other coroners and medical examiners in a variety of geographic areas. Completion of this continuation project is scheduled for late 2006.

Appendix A: Interview Schedule for Mark Malcolm and his Staff

Nursing Home Care

- Did you have any thoughts or opinions about nursing home care before you became involved with these investigations?

- Have you had anyone close to you in a nursing home? What were your impressions of the care they received (both positive and negative)? Probe: What qualities or characteristics did that particular nursing home or the employees within the nursing home have that influenced the type of care the resident received? You might think about the environment in the home, the characteristics of the nursing home, and/or the characteristics of the staff.

Investigation Process and Role

- Outline the investigation process. [How long does an investigation take?]

- Has this process changed over the past three years or since you've been in this position? What brought about those changes?

- What is your particular role in the investigation? How long have you been involved with the investigations? What type of training did you need to do this work OR what is your training background?

- Has how you've done your job changed over the past three years or since you've been involved in the investigations? How so?

- How are these investigations different than other investigations?

Critical Incident(s)

- In general, what initial findings or factors move you or the staff to pursue further investigation? In other words, what are the red flags?

- Tell me about a particular investigation where you strongly suspected abuse or neglect. What were the characteristics of the situation and what made you suspect abuse or neglect?

- Have there been people sent for autopsy in whom you were surprised to find no significant indicators of mistreatment? Tell me about one of those incidences. What was the ultimate outcome and why was that conclusion reached? Do you encounter many of these "gray cases"?

- Without naming a specific nursing home, are there nursing homes in this county that you consider at a higher risk of deaths from abuse or neglect? How do they differ from homes with lesser or no risk for abuse or neglect?

- In cases of verified abuse or neglect, have there been striking similarities among the victims or facilities in those cases? If so, describe those similarities.

Barriers and Facilitators to Investigation

- What are some barriers to the investigation process? Do barriers come at different points or from different people in the investigation process?

    - Are nursing homes hostile toward you when you arrive? Is so, how do they express hostility?

- What or who helps to move the investigation process along? Can nursing homes help facilitate the investigation? How can they do that?

- Who tends to give you the most useful information: physicians, staff or family? What type of information do they give you? What makes their information useful?

- What types of information can you ***not*** get in these investigations? What would need to happen in order for you to get that information? Do you ever find yourself making a judgment call – maybe the hard evidence is not there but you suspect a problem or problems?

- Are there particular problems that come up that are out of your jurisdiction?

Legal Issues and Effects of the Law

- Do you think this new law has identified more mistreatment deaths than before the law began?

- What has been the reaction and response of law enforcement personnel (both police and attorneys) when they have been contacted by your office?

- How have the nursing homes changed since the law was passed? Have some homes changed more than others?

Classification Issues

- What would be your annual estimate of mistreatment deaths identified in your county?

- What percent of total nursing home deaths does this represent?

- Is the extra identification of neglect or abuse worth the added workload to your office?

- Do you feel that other office tasks have suffered as a result of this added workload? What tasks in particular?

- Have people in your office quit due to the change in the investigation procedure or because this procedure was implemented? What is your perception of why this happened?

- In your opinion, what are the biggest problems facilities face in terms of being able to provide care to their residents?

Ideal Procedures and Recommendations

- If you had unlimited personnel and funding, outline your ideal investigational procedure.

- Assuming your personnel and funding support stay the same, would you recommend any changes to the current investigational procedure? What specific changes would you recommend?

- Does the current law need altering? Could you make suggestions about how the law could be altered to better serve the people it is intended to help?

- Imagine that another coroner's office is considering the start of a similar program to yours, and you are called in as a consultant. What advice would you offer so that office would avoid the investigational problems that you have encountered?

- Is referring more autopsies a goal of your office? What are the positive impacts of autopsies? What are the negative impacts?

- What do you like and dislike about your job in relation to these nursing home death investigations?

- In general, how do you feel about these investigations? What is the overall sentiment of your facility to the investigations? Could you make suggestions about how the investigations could be adjusted to better serve the people they are intended to help?

- In general, how do you feel about this law? What is the overall sentiment of your facility to this law? Could you make suggestions about how the law could be altered or rewritten to better serve the people it is intended to help?

Additional Comments

- Are there questions that I did not ask that you believe I should have asked?

- Are there any other comments you would like to make? Any questions?

Appendix B: Coroner/ME Focus Group Moderator Guide

INTRODUCTION *(5 min.)*

Thank you for coming.

We really appreciate your help. You are the experts here today, and we want to give people a chance to tell us what their experiences have been and what your advice and opinion you can offer us.

The purpose of this focus group discussion is to learn about your experience and views on how to identify deaths among nursing home residents that are a result of abuse or neglect. We can't solve all problems in nursing homes with this project, but we can learn from you about how to recognize mistreatment that leads to death and potentially how to recognize risk factors for fatal abuse and neglect so that we can prevent or at least minimize such events.

As you know, this is a study funded by the U.S. Department of Justice. Three of the staff from the study are here today. My name is _____, and I will be moderating the group discussion, just to ensure that we cover all the topics and that everyone in the group has an opportunity to speak his or her mind. At the end of the table is _____. He/she will take notes so I don't have to worry about it. _____ will be minding the tape recorder, if you all agree to have the focus group session tape-recorded.

Everyone in the group is encouraged to speak his or her mind, and tell about his or her experiences or opinions on the topics being discussed. There are no right or wrong answers. We want to hear what ***you*** think. We also want to know where your opinions differ from each other and when you agree.

I'm not planning to do most of the talking. I do have several things for you to talk about, though, so I'll try to keep things moving along. Please don't be offended if I ask the group to move to another topic before you have had a chance to say everything you wanted to. I'll try to leave time at the end of the session for each of you to say something you did not get a chance to mention.

There is no need to raise hands. Speak right up, but please respect others when they are talking. Also, when the discussion is over, please respect the privacy of your fellow group members.

As you know from the informed consent form, what you say will be kept confidential by project staff. We will report what is said in this meeting without identifying any comment or suggestion as coming from a particular participant. We are recording the session merely to ensure that we "hear" all your comments and suggestions and do so accurately.

Does anyone have any problems or concerns about this? Can everyone stay for the two hours? Good. Then let's begin.

1. Why don't we start by going around the room and letting each person introduce himself or herself and say something about how you came to be working in a coroner's or medical examiner's office. ***(10-15 min.)***

2. Does your office have any specific mandate to review the deaths of nursing home residents? ***(10-15 min)***

3. How often does your office review deaths of nursing home residents, and if so, what tends to trigger or initiate that review? ***(15 min)***

   Possible probes: Do you receive calls from hospitals about suspicious deaths? From other health care professionals? From funeral homes?

4. What are the factors about a particular death of a nursing home resident that make your office undertake an initial review and what kinds of factors or findings move the case from an initial review to more in-depth examination or autopsy? ***(30 min)***

   Possible probes: Are their certain types of residents whose deaths raise a flag? Are there certain characteristics of the deceased, such as pressure ulcers or malnutrition, that prompt a review by your office?

5. In your experience, do you think there are certain types of nursing homes or certain characteristics of nursing homes that make one more likely than another to have deaths associated with mistreatment? ***(20-30 min)***

6. What kinds of barriers or constraints would face your office if you wanted to expand your office's role in investigating deaths of nursing home residents? ***(20 min)***

   Possible probes: What about resources to do this? What about the expertise to recognize abuse and neglect? Would the police and district attorney follow up on any findings you made about abuse or neglect causing a death? Would families cooperate or object?

Appendix C: Geriatrician Focus Group Survey

The results of this survey will be used for descriptive purposes only and not to identify any of the participants or associate names with your remarks in the write-up of the focus group interviews.

1. What is your first name *(only)*? _____

2. Which of the following professional degrees do you hold? *(CIRCLE ALL THAT APPLY)*

   a. LPN or LVN 01

   b. RN 02

   c. MSN (or comparable degree).. 03

   d. Therapist (PT, OT, etc.) 04

   e. BSSW or MSW 05

   f. Licensed nursing home administrator 06

   g. Ph.D. 07

   h. M.D. 08

   i. D.O. 09

   j. Board-certified in geriatric medicine 10

   k. Board-certified in forensic medicine 11

   l. Other health care professional (Specify) _____ 12

   m. *NONE OF THE ABOVE* 13

3. Are you or have you ever been a Medical Director of a nursing home? *(CIRCLE THE CORRECT RESPONSE)*

		Yes	No
a.	Currently a Medical Director	01	02
b.	Previously a Medical Director	01	02
c.	Never a Medical Director	01	02

4. Do you have or have you ever had patients who were residents in nursing homes?

   a. Yes 01

   b. No 02

5. In what state is your practice located? _____

6. How would you describe your the geographic location of your office *(CIRCLE THE RESPONSE THAT MOST ACCURATELY DESCRIBES IT)*

   a. Large metropolitan area (e.g., MSA population > one million)
   b. Medium-sized metropolitan area (MSA population 250 – 999,999)
   c. Smaller metropolitan area (e.g., population 50,000 – 249,999)
   d. Smaller city or metropolitan area (e.g., population 5,000 – 49,999)
   e. Small town (e.g., population < 5,000)
   f. Largely rural/isolated county/area
   g. Other (explain) _____

7. Please provide information about any other experience you have had related to nursing homes: *(CIRCLE THE CORRECT RESPONSE FOR EACH ITEM*)

	YES	***NO***
a. Worked for state survey agency	01	02
b. Worked for a nursing facility/nursing home	01	02
If "YES," what position(s): _____		
c. Worked for an industry/provider trade association	01	02
d. Worked for a consumer/advocacy group	01	02
e. Was a family member of a resident	01	02

THANK YOU FOR YOUR ASSISTANCE

Appendix D: MDS Item Summary by Comparison Group (Significant Differences between Listed and Non-Listed Deaths)

- "AG vs. Non-AG p-value" tests the assumption that the MDS item value distribution is the same for the "Listed AG Deaths" and the "Listed Non-AG Deaths". Small p-values indicate that the assumption of equality is unlikely.

- "All Deaths p-value" tests the assumption that the MDS item value distribution is the same for "Listed AG Deaths", "Listed Non-AG Deaths", and "Non-Listed Deaths".

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
Count		20	375	4,682	29,592	34,669		
B5B - Altered Perception	OK	75.0	81.3	72.5	80.9	79.8		
	Present, not recent	25.0	16.0	23.4	17.3	18.1		
	Present, recent onset		0.8	2.8	1.3	1.5	55.9%	0.1%
E1E - Self Deprecation	Not exhibited	100.0	95.5	97.5	98.3	98.2		
	Up to 5 times/wk		2.7	1.0	0.9	1.0		
	Almost daily			0.2	0.1	0.1	45.5%	0.9%
E1K - Insomnia	Not exhibited	100.0	96.0	92.2	94.5	94.2		
	Up to 5 times/wk		1.9	5.1	3.7	3.9		
	Almost daily		0.3	1.3	1.1	1.1	80.1%	1.3%
E1N - Repetitive Movements	Not exhibited	95.0	88.0	83.9	88.0	87.4		
	Up to 5 times/wk	5.0	4.0	8.5	6.3	6.6		
	Almost daily		5.9	6.4	5.1	5.3	52.4%	2.4%
G1AA - Bed Mobility	Independent	35.0	28.8	19.1	42.8	39.5		
	Supervision		3.5	4.1	6.7	6.3		
	Limited Assistance	5.0	16.3	15.7	18.4	18.0		
	Extensive Assistance	15.0	18.9	22.7	14.5	15.7		
	Total Dependence	45.0	32.5	38.3	17.6	20.5		
	Activity Not Occur			0.1	0.0	0.0	47.4%	0.1%
G1BA - Transfer	Independent	20.0	13.1	9.0	26.1	23.7		
	Supervision	5.0	3.5	3.3	8.5	7.8		
	Limited Assistance	10.0	19.5	13.9	22.0	20.9		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Extensive Assistance	10.0	22.9	25.4	18.9	19.9		
	Total Dependence	55.0	38.9	43.3	23.0	25.9		
	Activity Not Occur		2.1	5.1	1.4	1.9	44.2%	0.1%
G1EA - Locomotion on Unit	Independent	30.0	22.4	12.1	31.6	28.9		
	Supervision	5.0	6.4	5.5	11.0	10.2		
	Limited Assistance	10.0	15.5	13.0	19.2	18.3		
	Extensive Assistance	5.0	10.9	12.7	9.7	10.1		
	Total Dependence	45.0	37.3	45.3	23.7	26.8		
	Activity Not Occur	5.0	7.5	11.4	4.9	5.8	85.0%	0.0%
G1FA - Locomotion off Unit	Independent	30.0	18.4	9.2	26.5	24.1		
	Supervision	5.0	4.5	5.2	10.3	9.5		
	Limited Assistance	10.0	14.4	12.6	16.4	15.8		
	Extensive Assistance		10.1	10.8	8.7	9.0		
	Total Dependence	50.0	39.7	44.9	27.1	29.6		
	Activity Not Occur	5.0	12.8	17.2	11.1	11.9	40.8%	0.0%
G1GA - Dressing	Independent	5.0	3.2	3.1	11.6	10.4		
	Supervision		2.1	2.6	9.4	8.4		
	Limited Assistance	25.0	20.8	15.7	27.0	25.4		
	Extensive Assistance	10.0	24.5	28.0	23.0	23.7		
	Total Dependence	60.0	48.3	45.0	24.4	27.4		
	Activity Not Occur		1.1	5.6	4.6	4.7	66.8%	0.2%
G1HA - Eating	Independent	45.0	25.1	20.7	47.6	43.7		
	Supervision	10.0	18.1	14.1	19.6	18.8		
	Limited Assistance	10.0	8.8	11.1	8.8	9.1		
	Extensive Assistance	5.0	8.3	12.7	6.4	7.3		
	Total Dependence	30.0	38.9	40.2	17.3	20.6		
	Activity Not Occur		0.8	1.2	0.3	0.5	48.8%	1.4%
G4AA - Neck ROM	No limitation	95.0	94.9	90.2	94.6	94.0		
	Limited on one side		0.8	2.5	1.6	1.7		
	Limited on both sides	5.0	4.3	7.3	3.8	4.3	91.2%	3.6%
G4AB - Neck Voluntary Movement	No loss	95.0	94.7	90.3	94.6	94.0		
	Partial loss	5.0	3.7	8.1	4.6	5.1		
	Full loss		1.6	1.6	0.8	0.9	81.9%	4.6%

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
G4BB - Arm Voluntary Movement	No loss	60.0	75.7	73.0	78.5	77.7		
	Partial loss	30.0	15.2	20.5	16.4	17.0		
	Full loss	10.0	9.1	6.5	5.1	5.3	19.7%	3.3%
G4DB - Leg Voluntary Movement	No loss	40.0	61.1	53.8	61.3	60.3		
	Partial loss	40.0	26.4	34.7	30.6	31.1		
	Full loss	20.0	12.5	11.5	8.2	8.7	17.2%	1.2%
G4EB - Foot Voluntary Movement	No loss	65.0	72.3	63.6	70.6	69.7		
	Partial loss	25.0	15.2	24.8	20.9	21.4		
	Full loss	10.0	12.5	11.6	8.4	8.9	49.7%	0.2%
G4FA - Other ROM	No limitation	100.0	97.6	93.8	95.4	95.2		
	Limited on one side		1.3	1.8	1.5	1.6		
	Limited on both sides		0.8	4.4	3.1	3.2	80.4%	1.0%
G4FB - Other Voluntary Movement	No loss	100.0	98.4	93.7	95.4	95.2		
	Partial loss		1.6	5.0	3.6	3.8		
	Full loss			1.3	0.9	1.0	56.9%	0.0%
G6A - Bedfast	No	80.0	83.5	73.6	90.6	88.2		
	Yes	20.0	16.5	26.4	9.4	11.8	68.6%	0.0%
J2B - Pain Intensity	Mild	15.0	14.9	11.2	12.0	12.0		
	Moderate	30.0	16.8	26.4	26.3	26.2		
	Horrible/Excruciating	10.0	4.3	5.4	2.6	3.0	61.5%	0.3%
J5A - Status Unstable	No	75.0	56.8	49.9	65.5	63.3		
	Yes	25.0	43.2	50.1	34.5	36.7	10.8%	0.3%
J5D - None of the Above	No	45.0	50.7	59.2	39.9	42.6		
	Yes	55.0	49.3	40.8	60.1	57.4	62.1%	0.3%
K3A - Weight Loss	No	75.0	80.0	73.2	86.7	84.8		
	Yes	25.0	20.0	26.7	13.2	15.1	58.8%	1.8%
N1A - Awake in Morning	No	25.0	14.1	22.4	11.2	12.7		
	Yes	75.0	85.9	77.6	88.8	87.3	18.1%	0.1%
N1D - None of the Above	No	95.0	92.8	85.2	95.5	94.0		
	Yes	5.0	7.2	14.8	4.5	6.0	70.9%	0.0%

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
O4D - Days of Hypnotics	Mean	-	0.08	0.23	0.32	0.31		
	Std. Dev.	-	0.67	1.18	1.33	1.31		
	Std. Dev. of Mean	-	0.03	0.02	0.07	0.02	60.4%	2.8%
O4E - Days of Diuretics	Mean	1.75	2.23	2.77	2.53	2.56		
	Std. Dev.	3.03	3.19	3.34	3.27	3.28		
	Std. Dev. of Mean	0.68	0.16	0.05	0.16	0.05	51.2%	0.4%
P4C - Trunk Restraint	Not Used	80.0	77.6	83.7	88.0	87.3		
	Less than daily		1.3	1.3	0.8	0.9		
	Used daily	20.0	21.1	15.0	11.2	11.8	86.5%	3.2%
Q2 - Change in Needs	No change	70.0	62.9	60.1	70.7	69.2		
	Improved		4.8	2.7	10.1	9.1		
	Deteriorated	30.0	32.3	37.2	19.1	21.7	56.5%	5.0%

In most of the cases listed in Appendix D, low p-values were probably the result of the large number of Non-Listed Deaths (29,592). In other words, even small differences between Listed and Non-Listed Deaths would be statistically significant due to the large sample size. Statistical significance and practical value are not synonymous, and further study would be needed before any of these items were considered valuable in determining suspicion for mistreatment.

Appendix E: MDS Item Summary by Comparison Group (Complete Listing)

- "AG vs. Non-AG p-value" tests the assumption that the MDS item value distribution is the same for the "Listed AG Deaths" and the "Listed Non-AG Deaths". Small p-values indicate that the assumption of equality is unlikely.

- "All Deaths p-value" tests the assumption that the MDS item value distribution is the same for "Listed AG Deaths", "Listed Non-AG Deaths", and "Non-Listed Deaths".

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
Count		20	375	4,682	29,592	34,669		
B1 - Comatose	No	100.0	98.4	98.7	99.4	99.3		
	Yes		1.6	1.3	0.6	0.7	56.9%	76.4%
B2A - ST Memory	OK	20.0	14.7	18.1	37.5	34.6		
	Problem	80.0	83.5	80.6	61.9	64.6	54.0%	26.3%
B2B - LT Memory	OK	40.0	25.6	30.1	49.4	46.5		
	Problem	60.0	72.5	68.5	49.9	52.7	17.1%	12.7%
B4 - Cog. Skills	Independent	25.0	9.1	11.4	27.7	25.3		
	Mod. Ind.	20.0	15.5	15.4	21.0	20.2		
	Mod. Impaired	20.0	34.7	35.7	31.5	32.1		
	Sev. Impaired	35.0	39.2	36.2	19.2	21.7	9.7%	27.0%
B5A - Easily Distracted	OK	75.0	77.1	70.4	76.7	75.8		
	Present, not recent	20.0	21.3	26.3	21.7	22.3		
	Present, recent onset	5.0		2.0	1.0	1.2	0.0%	0.7%
B5B - Altered Perception	OK	75.0	81.3	72.5	80.9	79.8		
	Present, not recent	25.0	16.0	23.4	17.3	18.1		
	Present, recent onset		0.8	2.8	1.3	1.5	55.9%	0.1%
B5C - Disorganized Speech	OK	75.0	74.1	68.9	78.9	77.5		
	Present, not recent	25.0	21.9	26.5	19.3	20.3		
	Present, recent onset		2.1	3.3	1.2	1.5	78.0%	16.6%
B5D - Restlessness	OK	85.0	76.3	73.3	80.6	79.5		
	Present, not recent	15.0	20.3	22.4	17.5	18.2		
	Present, recent onset		1.6	3.0	1.3	1.6	68.6%	29.4%

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
B5E - Lethargy	OK	70.0	76.8	72.6	89.5	87.1		
	Present, not recent	25.0	18.4	19.8	8.7	10.3		
	Present, recent onset	5.0	2.9	6.3	1.2	1.9	66.9%	9.3%
B5F - Mental Function Varies	OK	55.0	60.5	65.4	73.5	72.3		
	Present, not recent	45.0	35.2	29.8	24.5	25.3		
	Present, recent onset		2.4	3.5	1.5	1.7	58.8%	8.3%
C4 - Making Self Understood	Always understood	55.0	36.8	37.3	58.6	55.5		
	Usually	10.0	22.7	22.7	19.7	20.2		
	Sometimes	25.0	24.0	21.8	12.8	14.1		
	Rarely	10.0	14.7	16.9	8.2	9.5	35.0%	48.6%
C6 - Ability to Understand	Always understands	45.0	32.0	31.6	51.8	48.9		
	Usually	25.0	28.3	26.2	25.0	25.2		
	Sometimes	15.0	25.3	27.0	16.0	17.6		
	Rarely	15.0	12.5	13.9	6.6	7.7	58.8%	72.7%
E1A - Negative Statements	Not exhibited	95.0	95.2	94.4	96.9	96.5		
	Up to 5 times/wk	5.0	2.4	3.6	2.1	2.3		
	Almost daily		0.5	0.7	0.4	0.4	74.2%	78.2%
E1B - Repetitive Questions	Not exhibited	95.0	92.3	93.5	93.7	93.6		
	Up to 5 times/wk	5.0	4.0	3.2	3.6	3.6		
	Almost daily		1.9	2.0	2.1	2.1	81.0%	86.7%
E1C - Repetitive Verbalizations	Not exhibited	85.0	88.0	89.0	93.3	92.7		
	Up to 5 times/wk	10.0	6.1	5.8	3.6	4.0		
	Almost daily	5.0	4.0	4.0	2.4	2.6	77.9%	93.9%
E1D - Persistent Anger	Not exhibited	90.0	87.2	85.2	86.6	86.4		
	Up to 5 times/wk	10.0	8.5	10.0	9.8	9.8		
	Almost daily		2.4	3.5	3.0	3.1	76.8%	58.7%
E1E - Self Deprecation	Not exhibited	100.0	95.5	97.5	98.3	98.2		
	Up to 5 times/wk		2.7	1.0	0.9	1.0		
	Almost daily			0.2	0.1	0.1	45.5%	0.9%
E1F - Unrealistic Fears	Not exhibited	100.0	95.7	94.3	95.2	95.1		
	Up to 5 times/wk		1.6	3.4	3.2	3.2		
	Almost daily		0.8	0.9	0.9	0.9	77.9%	33.2%
E1G - Foreboding	Not exhibited	100.0	97.1	96.3	97.9	97.7		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Up to 5 times/wk		0.5	1.7	1.2	1.3		
	Almost daily		0.5	0.7	0.3	0.3	89.6%	45.8%
E1H - Health Complaints	Not exhibited	95.0	92.3	89.1	90.4	90.3		
	Up to 5 times/wk	5.0	4.5	6.0	5.8	5.8		
	Almost daily		1.3	3.6	3.1	3.1	87.0%	10.6%
E1I - Non-Health Complaints	Not exhibited	95.0	92.0	88.6	87.6	87.8		
	Up to 5 times/wk	5.0	4.8	6.7	8.2	7.9		
	Almost daily		1.3	3.4	3.6	3.5	87.1%	9.9%
E1J - Unpleasant in Morning	Not exhibited	95.0	94.9	94.4	96.0	95.8		
	Up to 5 times/wk		1.9	3.1	2.5	2.6		
	Almost daily	5.0	1.3	1.2	0.8	0.9	36.6%	33.8%
E1K - Insomnia	Not exhibited	100.0	96.0	92.2	94.5	94.2		
	Up to 5 times/wk		1.9	5.1	3.7	3.9		
	Almost daily		0.3	1.3	1.1	1.1	80.1%	1.3%
E1L - Worried Facial Expressions	Not exhibited	85.0	72.5	69.8	78.3	77.1		
	Up to 5 times/wk	5.0	18.9	17.8	15.2	15.6		
	Almost daily	10.0	6.7	11.1	5.9	6.6	26.2%	5.1%
E1M - Crying	Not exhibited	95.0	92.5	91.1	93.4	93.1		
	Up to 5 times/wk		4.5	6.2	5.1	5.2		
	Almost daily	5.0	1.1	1.5	0.9	1.0	20.4%	29.7%
E1N - Repetitive Movements	Not exhibited	95.0	88.0	83.9	88.0	87.4		
	Up to 5 times/wk	5.0	4.0	8.5	6.3	6.6		
	Almost daily		5.9	6.4	5.1	5.3	52.4%	2.4%
E1O - Lack of Interest	Not exhibited	95.0	88.8	86.1	92.2	91.3		
	Up to 5 times/wk	5.0	4.8	7.0	4.8	5.1		
	Almost daily		4.5	5.6	2.4	2.9	61.7%	29.4%
E1P - Reduced Interaction	Not exhibited	90.0	88.0	82.8	90.8	89.7		
	Up to 5 times/wk	5.0	5.3	8.8	5.8	6.2		
	Almost daily	5.0	4.8	7.2	2.8	3.4	99.6%	5.5%
E2 - Mood Persistence	No Indicators	70.0	57.9	52.1	60.2	59.1		
	Present, easily altered	5.0	16.0	19.9	19.9	19.9		
	Present, not easily altered	25.0	24.3	26.7	19.2	20.3	38.1%	5.9%
E4AA - Wandering -	Not exhibited	90.0	92.3	92.7	91.8	91.9		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
Frequency								
	Exhibited 1-3 of 7 days		1.3	2.6	2.8	2.8		
	Exhibited 4-6 of 7 days		2.1	1.1	1.5	1.4		
	Exhibited daily	10.0	2.7	2.3	3.3	3.2	26.1%	8.9%
E4AB - Wandering - Alterability	Not present or easily altered	90.0	93.9	94.8	94.7	94.7		
	Present, not easily altered	10.0	4.5	4.0	4.8	4.6	27.6%	34.5%
E4BA - Verbally Abusive - Frequency	Not exhibited	80.0	88.3	88.5	89.6	89.5		
	Exhibited 1-3 of 7 days	10.0	6.4	6.3	6.7	6.7		
	Exhibited 4-6 of 7 days	5.0	2.4	2.7	2.0	2.1		
	Exhibited daily	5.0	1.3	1.2	1.0	1.0	44.6%	75.5%
E4BB - Verbally Abusive - Alterability	Not present or easily altered	80.0	91.2	91.8	93.2	93.0		
	Present, not easily altered	20.0	7.2	6.9	6.2	6.3	4.1%	7.4%
E4CA - Physically Abusive - Frequency	Not exhibited	85.0	91.7	90.5	93.3	92.9		
	Exhibited 1-3 of 7 days	5.0	4.3	5.1	4.4	4.5		
	Exhibited 4-6 of 7 days	5.0	1.1	2.0	1.1	1.2		
	Exhibited daily	5.0	1.3	1.1	0.6	0.7	25.6%	45.4%
E4CB - Physically Abusive - Alterability	Not present or easily altered	85.0	93.9	93.0	95.4	95.1		
	Present, not easily altered	15.0	4.5	5.7	4.0	4.3	4.0%	13.1%
E4DA - Socially Disruptive - Frequency	Not exhibited	80.0	82.4	85.4	87.4	87.1		
	Exhibited 1-3 of 7 days	10.0	6.4	6.5	6.2	6.3		
	Exhibited 4-6 of 7 days		4.3	3.4	2.8	2.9		
	Exhibited daily	10.0	5.1	3.4	3.0	3.1	55.8%	27.8%
E4DB - Socially Disruptive - Alterability	Not present or easily altered	80.0	85.9	89.2	90.9	90.6		
	Present, not easily altered	20.0	12.3	9.5	8.5	8.7	33.0%	6.9%
E4EA - Resists Care - Frequency	Not exhibited	65.0	75.2	73.0	80.0	79.0		
	Exhibited 1-3 of 7 days	25.0	11.2	13.1	12.1	12.2		
	Exhibited 4-6 of 7 days	10.0	7.2	6.3	4.1	4.4		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Exhibited daily		4.5	6.3	3.2	3.6	22.8%	28.6%
E4EB - Resists Care - Alterability	Not present or easily altered	70.0	82.1	78.7	85.3	84.4		
	Present, not easily altered	30.0	16.0	20.1	14.1	14.9	11.2%	9.7%
G1AA - Bed Mobility	Independent	35.0	28.8	19.1	42.8	39.5		
	Supervision		3.5	4.1	6.7	6.3		
	Limited Assistance	5.0	16.3	15.7	18.4	18.0		
	Extensive Assistance	15.0	18.9	22.7	14.5	15.7		
	Total Dependence	45.0	32.5	38.3	17.6	20.5		
	Activity Not Occur			0.1	0.0	0.0	47.4%	0.1%
G1BA - Transfer	Independent	20.0	13.1	9.0	26.1	23.7		
	Supervision	5.0	3.5	3.3	8.5	7.8		
	Limited Assistance	10.0	19.5	13.9	22.0	20.9		
	Extensive Assistance	10.0	22.9	25.4	18.9	19.9		
	Total Dependence	55.0	38.9	43.3	23.0	25.9		
	Activity Not Occur		2.1	5.1	1.4	1.9	44.2%	0.1%
G1CA - Walk in Room	Independent	15.0	9.3	8.4	24.0	21.7		
	Supervision	10.0	5.3	3.1	8.7	7.9		
	Limited Assistance	10.0	9.9	10.2	18.3	17.1		
	Extensive Assistance	10.0	8.8	9.7	9.7	9.7		
	Total Dependence		0.5	1.8	1.5	1.5		
	Activity Not Occur	55.0	66.1	66.8	37.9	42.1	86.6%	19.8%
G1DA - Walk in Corridor	Independent	10.0	7.5	6.1	19.5	17.5		
	Supervision	10.0	5.3	3.5	9.9	9.0		
	Limited Assistance		8.8	8.7	17.3	16.1		
	Extensive Assistance	10.0	5.6	6.1	7.8	7.6		
	Total Dependence			1.2	1.0	1.0		
	Activity Not Occur	70.0	72.8	74.4	44.5	48.8	50.7%	7.4%
G1EA - Locomotion on Unit	Independent	30.0	22.4	12.1	31.6	28.9		
	Supervision	5.0	6.4	5.5	11.0	10.2		
	Limited Assistance	10.0	15.5	13.0	19.2	18.3		
	Extensive Assistance	5.0	10.9	12.7	9.7	10.1		
	Total Dependence	45.0	37.3	45.3	23.7	26.8		
	Activity Not Occur	5.0	7.5	11.4	4.9	5.8	85.0%	0.0%

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
G1FA - Locomotion off Unit	Independent	30.0	18.4	9.2	26.5	24.1		
	Supervision	5.0	4.5	5.2	10.3	9.5		
	Limited Assistance	10.0	14.4	12.6	16.4	15.8		
	Extensive Assistance		10.1	10.8	8.7	9.0		
	Total Dependence	50.0	39.7	44.9	27.1	29.6		
	Activity Not Occur	5.0	12.8	17.2	11.1	11.9	40.8%	0.0%
G1GA - Dressing	Independent	5.0	3.2	3.1	11.6	10.4		
	Supervision		2.1	2.6	9.4	8.4		
	Limited Assistance	25.0	20.8	15.7	27.0	25.4		
	Extensive Assistance	10.0	24.5	28.0	23.0	23.7		
	Total Dependence	60.0	48.3	45.0	24.4	27.4		
	Activity Not Occur		1.1	5.6	4.6	4.7	66.8%	0.2%
G1HA - Eating	Independent	45.0	25.1	20.7	47.6	43.7		
	Supervision	10.0	18.1	14.1	19.6	18.8		
	Limited Assistance	10.0	8.8	11.1	8.8	9.1		
	Extensive Assistance	5.0	8.3	12.7	6.4	7.3		
	Total Dependence	30.0	38.9	40.2	17.3	20.6		
	Activity Not Occur		0.8	1.2	0.3	0.5	48.8%	1.4%
G1IA - Toilet Use	Independent	15.0	9.1	6.2	20.4	18.3		
	Supervision	5.0	1.1	2.8	8.1	7.3		
	Limited Assistance	10.0	11.5	12.3	21.6	20.2		
	Extensive Assistance	15.0	19.7	22.0	18.2	18.7		
	Total Dependence	50.0	57.3	54.7	30.6	34.2		
	Activity Not Occur	5.0	1.3	2.1	1.1	1.2	39.8%	14.1%
G1JA - Personal Hygiene	Independent	5.0	4.5	3.0	12.0	10.7		
	Supervision		2.7	3.4	11.2	10.0		
	Limited Assistance	25.0	16.8	14.9	26.3	24.6		
	Extensive Assistance	10.0	22.1	22.7	20.2	20.6		
	Total Dependence	60.0	53.9	56.1	30.2	34.0		
	Activity Not Occur			0.0	0.0	0.0	60.7%	42.4%
G2A - Bathing	Independent		1.1	0.3	2.5	2.2		
	Supervision		1.1	1.3	6.5	5.8		
	Physical Help Transfer	20.0	5.1	4.2	13.5	12.1		
	Physical Help Bathing	25.0	32.5	30.9	40.7	39.3		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Total Dependence	55.0	60.0	63.2	36.8	40.6		
	Activity Not Occur		0.3	0.1	0.1	0.1	14.7%	2.2%
G4AA - Neck ROM	No limitation	95.0	94.9	90.2	94.6	94.0		
	Limited on one side		0.8	2.5	1.6	1.7		
	Limited on both sides	5.0	4.3	7.3	3.8	4.3	91.2%	3.6%
G4AB - Neck Voluntary Movement	No loss	95.0	94.7	90.3	94.6	94.0		
	Partial loss	5.0	3.7	8.1	4.6	5.1		
	Full loss		1.6	1.6	0.8	0.9	81.9%	4.6%
G4BA - Arm ROM	No limitation	60.0	74.7	73.2	77.9	77.2		
	Limited on one side	20.0	13.3	12.3	12.9	12.8		
	Limited on both sides	20.0	11.7	14.5	9.2	10.0	32.8%	38.1%
G4BB - Arm Voluntary Movement	No loss	60.0	75.7	73.0	78.5	77.7		
	Partial loss	30.0	15.2	20.5	16.4	17.0		
	Full loss	10.0	9.1	6.5	5.1	5.3	19.7%	3.3%
G4CA - Hand ROM	No limitation	70.0	76.8	74.2	79.4	78.7		
	Limited on one side	15.0	11.7	12.2	12.1	12.1		
	Limited on both sides	15.0	11.5	13.7	8.5	9.3	78.3%	76.4%
G4CB - Hand Voluntary Movement	No loss	70.0	77.1	73.6	79.3	78.5		
	Partial loss	25.0	14.1	19.0	14.9	15.5		
	Full loss	5.0	8.8	7.4	5.7	6.0	37.4%	16.4%
G4DA - Leg ROM	No limitation	40.0	59.7	53.4	59.7	58.8		
	Limited on one side	15.0	20.3	16.3	19.0	18.7		
	Limited on both sides	45.0	20.0	30.3	21.3	22.5	2.9%	0.0%
G4DB - Leg Voluntary Movement	No loss	40.0	61.1	53.8	61.3	60.3		
	Partial loss	40.0	26.4	34.7	30.6	31.1		
	Full loss	20.0	12.5	11.5	8.2	8.7	17.2%	1.2%
G4EA - Foot ROM	No limitation	65.0	72.0	63.9	70.4	69.6		
	Limited on one side	5.0	14.1	12.3	13.4	13.3		
	Limited on both sides	30.0	13.9	23.7	16.1	17.1	9.8%	0.0%
G4EB - Foot Voluntary	No loss	65.0	72.3	63.6	70.6	69.7		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
Movement								
	Partial loss	25.0	15.2	24.8	20.9	21.4		
	Full loss	10.0	12.5	11.6	8.4	8.9	49.7%	0.2%
G4FA - Other ROM	No limitation	100.0	97.6	93.8	95.4	95.2		
	Limited on one side		1.3	1.8	1.5	1.6		
	Limited on both sides		0.8	4.4	3.1	3.2	80.4%	1.0%
G4FB - Other Voluntary Movement	No loss	100.0	98.4	93.7	95.4	95.2		
	Partial loss		1.6	5.0	3.6	3.8		
	Full loss			1.3	0.9	1.0	56.9%	0.0%
G6A - Bedfast	No	80.0	83.5	73.6	90.6	88.2		
	Yes	20.0	16.5	26.4	9.4	11.8	68.6%	0.0%
G6B - Uses Bedrails	No	65.0	45.9	51.3	52.5	52.3		
	Yes	35.0	54.1	48.7	47.5	47.7	9.5%	5.7%
G6F - None of the Above	No	60.0	78.4	75.6	61.9	64.0		
	Yes	40.0	21.6	24.4	38.1	36.0	5.5%	12.4%
H1A - Bowel Incontinence	Continent	30.0	21.1	22.0	50.4	46.3		
	Usually continent	5.0	5.3	5.9	6.5	6.4		
	Usually incontinent	5.0	5.1	6.2	5.6	5.7		
	Frequently incontinent	5.0	6.7	8.7	6.6	6.9		
	Incontinent	55.0	61.9	57.2	30.8	34.7	92.0%	75.0%
H1B - Bladder Incontinence	Continent	50.0	31.5	34.9	45.4	43.8		
	Usually continent		5.3	4.9	8.3	7.8		
	Usually incontinent	10.0	3.5	6.0	7.4	7.2		
	Frequently incontinent	15.0	10.4	10.2	10.8	10.7		
	Incontinent	25.0	49.3	44.0	28.1	30.5	9.4%	13.6%
H2D - Fecal Impaction	No	100.0	99.7	99.3	99.7	99.6		
	Yes		0.3	0.7	0.3	0.4	81.7%	54.6%
H2E - None of the Above	No	45.0	49.3	51.6	46.5	47.2		
	Yes	55.0	50.7	48.4	53.5	52.8	70.6%	58.8%
H3A - Toileting Plan	No	85.0	85.1	85.0	85.7	85.6		
	Yes	15.0	14.9	15.0	14.3	14.4	99.3%	100.0%
H3B - Bladder Retraining	No	100.0	100.0	98.4	98.5	98.5		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Yes			1.6	1.5	1.5	100.0%	100.0%
H3C - External Catheter	No	100.0	100.0	99.7	99.9	99.8		
	Yes			0.3	0.1	0.2	100.0%	100.0%
H3D - Indwelling Catheter	No	65.0	80.3	75.8	87.7	86.0		
	Yes	35.0	19.7	24.2	12.3	14.0	9.9%	7.5%
H3I - Ostomy	No	90.0	96.5	95.7	97.1	96.9		
	Yes	10.0	3.5	4.3	2.9	3.1	13.6%	33.3%
H3J - None of the Above	No	70.0	60.3	64.5	42.7	45.8		
	Yes	30.0	39.7	35.5	57.3	54.2	38.5%	22.3%
I2J - UTI within 30 Days	No	80.0	82.7	84.8	89.9	89.1		
	Yes	20.0	17.3	15.2	10.1	10.9	76.0%	47.8%
I2M - None of the Above	No	30.0	30.7	31.4	21.1	22.6		
	Yes	70.0	69.3	68.6	78.9	77.4	95.0%	94.7%
J1C - Dehydrated	No	100.0	98.9	98.1	98.6	98.5		
	Yes		1.1	1.9	1.4	1.5	64.2%	42.4%
J1I - Hallucinations	No	95.0	98.7	97.3	98.1	98.0		
	Yes	5.0	1.3	2.7	1.9	2.0	19.1%	21.4%
J1P - None of the Above	No	60.0	64.5	69.3	66.6	66.9		
	Yes	40.0	35.5	30.7	33.4	33.1	68.0%	11.1%
J2A - Pain Frequency	No pain	45.0	64.0	57.0	59.1	58.9		
	Less than daily	25.0	17.6	19.0	20.7	20.4		
	Daily	30.0	18.4	24.0	20.2	20.7	22.2%	5.5%
J2B - Pain Intensity	Mild	15.0	14.9	11.2	12.0	12.0		
	Moderate	30.0	16.8	26.4	26.3	26.2		
	Horrible/Excruciating	10.0	4.3	5.4	2.6	3.0	61.5%	0.3%
J4A - Fell in Past 30 Days	No	85.0	84.5	83.0	83.9	83.8		
	Yes	15.0	15.5	17.0	16.1	16.2	95.5%	72.2%
J4B - Fell in Past 31-180 Days	No	80.0	81.1	79.1	80.1	79.9		
	Yes	20.0	18.9	20.8	19.9	20.1	90.6%	67.6%
J4C - Hip Fracture	No	100.0	97.3	96.5	96.6	96.6		
	Yes		2.7	3.5	3.4	3.4	45.9%	46.7%
J4D - Other Fracture	No	100.0	97.9	97.3	96.6	96.7		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Yes		2.1	2.7	3.4	3.3	50.9%	61.7%
J4E - None of the Above	No	30.0	32.5	34.1	33.0	33.1		
	Yes	70.0	67.5	65.9	67.0	66.9	81.4%	77.8%
J5A - Status Unstable	No	75.0	56.8	49.9	65.5	63.3		
	Yes	25.0	43.2	50.1	34.5	36.7	10.8%	0.3%
J5B - Acute/Chronic Episode	No	95.0	92.0	88.4	90.6	90.3		
	Yes	5.0	8.0	11.6	9.4	9.7	62.7%	6.8%
J5C - End-Stage Disease	No	75.0	91.7	89.4	98.1	96.8		
	Yes	25.0	8.3	10.6	1.9	3.2	1.1%	3.9%
J5D - None of the Above	No	45.0	50.7	59.2	39.9	42.6		
	Yes	55.0	49.3	40.8	60.1	57.4	62.1%	0.3%
K3A - Weight Loss	No	75.0	80.0	73.2	86.7	84.8		
	Yes	25.0	20.0	26.7	13.2	15.1	58.8%	1.8%
K3B - Weight Gain	No	100.0	93.6	94.2	93.3	93.4		
	Yes		6.4	5.7	6.6	6.5	24.3%	47.2%
K5B - Feeding Tube	No	80.0	85.3	87.0	93.2	92.2		
	Yes	20.0	14.7	13.0	6.8	7.7	51.4%	42.4%
K5H - Weight Program	No	75.0	77.9	77.7	85.5	84.4		
	Yes	25.0	22.1	22.3	14.5	15.6	76.4%	95.6%
K5I - None of the Above	No	65.0	66.7	70.0	53.5	55.9		
	Yes	35.0	33.3	30.0	46.5	44.1	87.8%	36.7%
M1A - Stage 1 Ulcer	Mean	0.15	0.15	0.14	0.06	0.07		
	Std. Dev.	0.65	0.65	0.54	0.34	0.38		
	Std. Dev. of Mean	0.15	0.03	0.01	0.02	0.01	98.9%	90.0%
M1A - Stage 1 Ulcer	None	95.0	90.7	90.7	95.6	94.8		
	1		6.4	6.6	3.3	3.7		
	2		2.1	1.8	0.8	0.9		
	3	5.0	0.3	0.6	0.3	0.3		
	4			0.1	0.1	0.1		
	5			0.1	0.0	0.0		
	6		0.3	0.0	0.0	0.0		
	7				0.0	0.0		
	8		0.3	0.0	0.0	0.0		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	9			0.0	0.0	0.0	6.8%	4.2%
M1B - Stage 2 Ulcer	Mean	0.35	0.29	0.36	0.14	0.17		
	Std. Dev.	0.73	0.88	0.91	0.56	0.63		
	Std. Dev. of Mean	0.16	0.05	0.01	0.03	0.01	75.8%	32.0%
M1B - Stage 2 Ulcer	None	75.0	82.7	78.7	91.1	89.3		
	1	20.0	12.3	13.0	5.8	6.9		
	2		2.7	5.2	2.0	2.4		
	3	5.0	1.1	1.7	0.5	0.7		
	4		0.5	0.4	0.2	0.3		
	5		0.3	0.4	0.1	0.2		
	6			0.1	0.1	0.1		
	7			0.1	0.0	0.1		
	8		0.3	0.1	0.0	0.0		
	9		0.3	0.1	0.0	0.0	76.2%	59.2%
M1C - Stage 3 Ulcer	Mean	0.60	0.07	0.08	0.03	0.04		
	Std. Dev.	1.98	0.37	0.42	0.27	0.30		
	Std. Dev. of Mean	0.44	0.02	0.01	0.01	0.00	0.0%	0.0%
M1C - Stage 3 Ulcer	None	85.0	95.5	94.6	97.9	97.4		
	1	5.0	2.9	4.0	1.5	1.8		
	2	5.0	1.1	0.9	0.4	0.5		
	3		0.3	0.2	0.1	0.1		
	4		0.3	0.1	0.0	0.0		
	5			0.1	0.0	0.0		
	6			0.0	0.0	0.0		
	7				0.0	0.0		
	8			0.0	0.0	0.0		
	9	5.0			0.0	0.0	0.1%	0.0%
M1D - Stage 4 Ulcer	Mean	0.10	0.09	0.08	0.03	0.03		
	Std. Dev.	0.30	0.46	0.46	0.25	0.29		
	Std. Dev. of Mean	0.07	0.02	0.01	0.01	0.00	94.8%	88.7%
M1D - Stage 4 Ulcer	None	90.0	94.9	95.2	98.4	97.9		
	1	10.0	2.4	3.0	1.1	1.4		
	2		1.3	1.0	0.4	0.5		
	3		1.1	0.3	0.1	0.1		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	4		0.3	0.2	0.1	0.1		
	5			0.1	0.0	0.0		
	6			0.0	0.0	0.0		
	7			0.0	0.0	0.0		
	8			0.0	0.0	0.0		
	9				0.0	0.0	34.0%	26.7%
M2A - Stage of Pressure Ulcer	None	65.0	76.5	71.4	88.0	85.7		
	1		4.0	5.0	2.6	2.9		
	2	15.0	11.5	15.7	6.6	7.9		
	3	10.0	2.9	3.6	1.4	1.7		
	4	10.0	5.1	4.3	1.4	1.9	27.9%	16.0%
M2B - Stage of Stasis Ulcer	None	100.0	96.5	97.1	98.2	98.1		
	1		0.3	0.2	0.2	0.2		
	2		2.4	1.5	1.0	1.1		
	3		0.5	0.7	0.3	0.4		
	4		0.3	0.4	0.2	0.2	94.9%	95.5%
N1A - Awake in Morning	No	25.0	14.1	22.4	11.2	12.7		
	Yes	75.0	85.9	77.6	88.8	87.3	18.1%	0.1%
N1B - Awake in Afternoon	No	10.0	28.3	31.2	16.9	19.0		
	Yes	90.0	71.7	68.8	83.1	81.0	7.4%	6.3%
N1C - Awake in Evening	No	35.0	67.7	54.4	42.6	44.5		
	Yes	65.0	32.3	45.6	57.4	55.5	0.3%	0.0%
N1D - None of the Above	No	95.0	92.8	85.2	95.5	94.0		
	Yes	5.0	7.2	14.8	4.5	6.0	70.9%	0.0%
N2 - Activity Time	Most	5.0	2.4	2.5	6.8	6.2		
	Some	65.0	57.6	52.3	71.1	68.4		
	Little	20.0	33.3	36.7	19.0	21.5		
	None	10.0	5.1	7.2	2.4	3.1	46.7%	24.4%
O1 - Number of Medications	Mean	7.55	8.00	8.28	8.61	8.56		
	Std. Dev.	3.85	3.65	4.54	4.48	4.48		
	Std. Dev. of Mean	0.86	0.19	0.07	0.23	0.06	59.4%	39.1%
O1 - Number of Medications	0	5.0	1.1	1.1	0.7	0.8		
	1		1.9	2.4	1.6	1.7		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	2	5.0	2.7	3.4	2.8	2.9		
	3		6.4	5.2	4.5	4.6		
	4	5.0	4.3	6.3	6.4	6.3		
	5	5.0	10.1	8.2	8.3	8.3		
	6	5.0	11.2	9.8	9.1	9.2		
	7	30.0	10.7	10.1	10.0	10.0		
	8	20.0	6.9	10.1	9.8	9.8		
	9	10.0	11.7	8.6	9.1	9.1		
	10	5.0	6.7	7.9	8.3	8.3		
	11		8.3	6.5	7.1	7.0		
	12	5.0	5.3	5.4	5.7	5.7		
	13		4.5	3.8	4.5	4.4		
	14		4.8	3.4	3.4	3.4		
	15		1.3	2.7	2.5	2.5		
	16		1.3	1.7	1.8	1.8		
	17		0.8	1.2	1.4	1.4		
	18			0.8	0.9	0.8		
	19			0.5	0.7	0.6		
	20	5.0		0.3	0.4	0.4		
	21			0.2	0.3	0.3		
	22			0.1	0.2	0.2		
	23			0.0	0.1	0.1		
	24			0.1	0.1	0.1		
	25			0.0	0.1	0.1		
	26				0.1	0.0		
	27			0.1	0.0	0.0		
	28				0.0	0.0		
	29			0.0	0.0	0.0		
	30				0.0	0.0		
	31				0.0	0.0		
	32				0.0	0.0		
	33			0.0		0.0		
	34				0.0	0.0		
	35					-		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	39					-		
	41				0.0	0.0		
	43					-		
	50				0.0	0.0		
	51					-		
	53				0.0	0.0		
	60				0.0	0.0		
	61				0.0	0.0		
	70			0.0		0.0		
	71					-		
	72					-		
	80				0.0	0.0		
	81			0.0		0.0		
	82				0.0	0.0		
	90			0.0	0.0	0.0		
	91				0.0	0.0		
	92				0.0	0.0		
	95				0.0	0.0		
	99				0.0	0.0	0.3%	0.1%
O4A - Days of Antipsychotics	Mean	2.10	1.41	1.33	1.46	1.44		
	Std. Dev.	3.21	2.78	2.70	2.81	2.80		
	Std. Dev. of Mean	0.72	0.14	0.04	0.14	0.04	28.4%	38.2%
O4A - Days of Antipsychotics	0	70.0	79.2	79.8	78.3	78.5		
	1		0.3	0.6	0.4	0.4		
	2			0.3	0.2	0.2		
	3			0.2	0.2	0.2		
	4		0.3	0.4	0.2	0.2		
	5		1.1	0.8	0.6	0.6		
	6			0.3	0.1	0.1		
	7	30.0	19.2	17.7	20.0	19.7	80.1%	53.3%
O4B - Days of Antianxiety Meds	Mean	0.80	0.86	0.90	0.90	0.90		
	Std. Dev.	2.11	2.24	2.24	2.25	2.25		
	Std. Dev. of Mean	0.47	0.12	0.03	0.11	0.03	90.0%	93.3%

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
O4B - Days of Antianxiety Meds	0	85.0	85.6	83.9	84.7	84.6		
	1		1.1	1.5	1.2	1.2		
	2	5.0	0.5	1.3	0.8	0.8		
	3		0.8	0.7	0.6	0.6		
	4		0.5	0.7	0.6	0.6		
	5		0.3	0.7	1.0	0.9		
	6			0.3	0.3	0.3		
	7	10.0	11.2	10.8	10.9	10.9	47.6%	79.6%
O4C - Days of Antidepressants	Mean	3.15	2.51	2.32	2.52	2.50		
	Std. Dev.	3.48	3.30	3.25	3.31	3.30		
	Std. Dev. of Mean	0.78	0.17	0.05	0.17	0.05	39.7%	29.9%
O4C - Days of Antidepressants	0	55.0	62.4	65.4	62.5	62.8		
	1		0.3	0.4	0.3	0.3		
	2		0.8	0.3	0.3	0.3		
	3		0.8	0.4	0.3	0.3		
	4			0.4	0.6	0.6		
	5		1.9	1.5	1.8	1.8		
	6			0.4	0.3	0.3		
	7	45.0	33.9	31.2	33.9	33.5	90.2%	41.4%
O4D - Days of Hypnotics	Mean	-	0.08	0.23	0.32	0.31		
	Std. Dev.	-	0.67	1.18	1.33	1.31		
	Std. Dev. of Mean	-	0.03	0.02	0.07	0.02	60.4%	2.8%
O4D - Days of Hypnotics	0	100.0	98.4	95.3	93.2	93.5		
	1			0.7	1.0	0.9		
	2		0.3	0.4	0.7	0.7		
	3		0.5	0.3	0.6	0.5		
	4			0.3	0.5	0.5		
	5			0.3	0.9	0.8		
	6			0.2	0.3	0.2		
	7		0.8	2.5	2.8	2.8	95.5%	5.7%
O4E - Days of Diuretics	Mean	1.75	2.23	2.77	2.53	2.56		

MDS Item	Value	Listed AG Death	Listed Non-AG Death	Non-Listed Death	Non-Death	Total	AG vs Non-AG p-value	All Deaths p-value
	Std. Dev.	3.03	3.19	3.34	3.27	3.28		
	Std. Dev. of Mean	0.68	0.16	0.05	0.16	0.05	51.2%	0.4%
O4E - Days of Diuretics	0	75.0	65.9	57.6	61.1	60.7		
	1		0.3	1.0	0.7	0.7		
	2		1.3	0.5	0.5	0.5		
	3		0.8	1.0	0.9	0.9		
	4		0.8	0.9	1.1	1.1		
	5		1.1	1.9	2.6	2.5		
	6			0.6	0.4	0.4		
	7	25.0	29.9	36.5	32.6	33.1	97.5%	4.2%
P4A - Full Bed Rails	Not Used	40.0	35.7	38.3	58.0	55.1		
	Less than daily		2.1	0.8	1.8	1.7		
	Used daily	60.0	62.1	60.9	40.3	43.3	76.5%	10.7%
P4B - Other Rails	Not Used	95.0	84.3	83.4	76.4	77.5		
	Less than daily		0.5	1.8	2.6	2.5		
	Used daily	5.0	15.2	14.8	21.0	20.1	42.5%	24.5%
P4C - Trunk Restraint	Not Used	80.0	77.6	83.7	88.0	87.3		
	Less than daily		1.3	1.3	0.8	0.9		
	Used daily	20.0	21.1	15.0	11.2	11.8	86.5%	3.2%
P4D - Limb Restraint	Not Used	100.0	98.7	98.7	99.5	99.4		
	Less than daily			0.3	0.1	0.1		
	Used daily		1.3	1.1	0.4	0.5	60.3%	48.2%
P4E - Chair Prevents Rising	Not Used	85.0	91.5	87.8	92.7	92.0		
	Less than daily	5.0	2.4	2.3	0.8	1.0		
	Used daily	10.0	6.1	9.9	6.5	6.9	59.4%	17.5%
Q2 - Change in Needs	No change	70.0	62.9	60.1	70.7	69.2		
	Improved		4.8	2.7	10.1	9.1		
	Deteriorated	30.0	32.3	37.2	19.1	21.7	56.5%	5.0%

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