

ARTICLE

# Crime, Incarceration, and Dementia: An Aging Criminal System

Jalayne J. Arias, JD, MA<sup>1</sup>, Lillian Morgado<sup>1</sup> and Ana Tyler<sup>2</sup>

<sup>1</sup>Georgia State University, Atlanta, GA, USA

<sup>2</sup>UCSF Memory and Aging Center, San Francisco, CA, USA

**Corresponding author:** Jalayne J. Arias; Email: [jarias@gsu.edu](mailto:jarias@gsu.edu)

## Abstract

Dementia within the criminal system, from arrest through incarceration, has been largely ignored. While the health system has begun grappling with the chronic conditions that will accompany an aging society, the criminal system has yet to meaningfully respond. Dementia is a clinical syndrome characterized by impairment in cognitive domains (memory, executive function, visuospatial). Additionally, dementia often includes behavioral symptoms that increase the likelihood that an individual's actions may violate social norms and in some circumstances be deemed criminal. Prior studies have established criminal behavior as a trend among individuals living with dementia. Yet, the criminal system has yet to establish protections for individuals who commit a crime while impaired by dementia. This paper will report on an empirical study to evaluate the treatment of persons with dementia within the criminal justice system. We will report on interviews with attorneys (n=15) regarding their experience and perspective on the treatment of persons with dementia post-arrest. In the paper, we will explore topics identified through these interviews including pre-trial release, competency, placement (housing), criminal liability determination, sentencing, and post-conviction release. We will highlight key findings including the lack of a systematic screening process for dementia post-arrest, placement is a significant challenge, attorneys' lack of training on dementia to be able to understand how the disease could impact decision-making, and the two legal mechanisms available to divert miss the mark given their focus on psychiatric populations. We will use these data and findings to argue for a research and policy agenda to address a gap in legal policies to appropriately manage persons with dementia post-arrest.

**Keywords:** Aging; dementia; criminal justice; ethics; Alzheimer's disease

## Introduction

The needs of older adults within the criminal justice system have been largely ignored.<sup>1</sup> Emerging evidence indicates that, much like other systems, the population within the criminal justice system is aging.<sup>2</sup> Along with it, the system must develop strategies and policies to manage and care for chronic conditions that are prevalent among older adults, including dementia.<sup>3</sup> Dementia is a clinical syndrome

<sup>1</sup>Rachael Bedard et al., *Aging In Jail: Retrospective Analysis Of Older Patients In New York City's Jail System, 2015–19*, 41 HEALTH AFF. (MILLWOOD) 732 (2022).

<sup>2</sup>Rachael Bedard, *Elderly, Detained, and Justice-Involved: The Most Incarcerated Generation*, 25 CITY UNIV. N. Y. LAW REV. 161 (2022); Bedard et al., *supra* note 1; Brie Williams, Michele DiTomas & Alison Pachynski, *The growing geriatric prison population: A dire public health consequence of mass incarceration*, 69 J. AM. GERIATR. SOC. 3407 (2021).

<sup>3</sup>Stephanie Grace Prost et al., *Standardized outcome measures of mental health in research with older adults who are incarcerated*, ahead-of-print INT. J. PRISON. HEALTH (2022); *Older adults in jail: high rates and early onset of geriatric conditions*, SPRINGERLINK, <https://link.springer.com/article/10.1186/s40352-018-0062-9> [<https://perma.cc/6998-PGMQ>] (last visited Jun 2, 2021); Cyrus Ahalt et al., *Cognition and Incarceration: Cognitive Impairment and Its Associated Outcomes in Older Adults in Jail*, 66 J. AM. GERIATR. SOC. 2065 (2018).

marked by cognitive and behavioral symptoms including deficits in memory, problem-solving, and thinking.<sup>4</sup> Multiple diseases can lead to cognitive impairment and dementia. The most common, Alzheimer's disease (AD), affects an estimated 6.5 million adults over sixty-five in the United States.<sup>5</sup> Frontotemporal lobar degeneration (FTLD) is the most common cause of young-onset dementia in adults under the age of sixty-five, including syndromes that are uniquely marked by behavioral symptoms.<sup>6</sup> There is evidence to show that individuals with dementia, of all causes, may experience symptoms causing behaviors and actions that lead to involvement with the criminal justice system (e.g., arrest). This risk is heightened in individuals with FTLD syndromes.<sup>7</sup> Additionally, individuals in custody are aging leading to increased rates of dementia within jails and prisons. Data from South Carolina shows that among individuals within the South Carolina Department of Corrections who had a dementia-related diagnosis, 11% were diagnosed with dementia before their arrest and 89% were diagnosed after arrest.<sup>8</sup> Despite increasing awareness that persons living with dementia (PLWD) may become justice-involved, there is minimal data describing rates of dementia at the time of arrest and a gap in understanding how the criminal justice system manages or cares for those with dementia.

This paper reports on a qualitative study using semi-structured interviews with legal practitioners to elicit their experience and professional insights on legal, policy, ethical, and logistical challenges to providing adequate care to PLWD who are justice-involved. We define "justice-involved" to mean persons who have interactions with the criminal justice system as a defendant or accused.<sup>9</sup> Our qualitative data uncovered significant intertwined legal, policy, ethical, and logistical barriers that impede providing adequate care to PLWD who are justice-involved. In this article, we explore the two overarching issues that are "linchpin" challenges to developing solutions that would support adequate care of PLWD who are justice-involved. First, we explore qualitative data on dementia detection—specifically when and how dementia is diagnosed or detected for persons post-arrest. This issue is central to identifying those who would benefit from improved policies, services, or programs. Second, we look at issues of placement or housing, which are essential to generating genuine solutions to other vexing problems. Our data also uncovered limitations of legal mechanisms currently available to PLWD or individuals experiencing dementia-related cognitive impairment, including competency determinations, affirmative defenses (e.g., not guilty by reason of insanity defense), and alternative sentencing options. We reserve reporting on specific details of that data for a later paper.

Ultimately, even if a criminal justice system was able to appropriately determine that a PLWD should not be held to the same criminal liability and sentencing standards as other individuals, the threshold questions remain: (1) how should the system identify individuals with dementia in the current system? And (2) where should PLWD be housed upon detecting dementia or cognitive impairment? Our data consistently show that the current criminal justice system applies the same standards and services to PLWD, as it would for individuals with psychiatric illness. We argue, based on our qualitative data and a review of the literature, that dementia requires new policies and system structures to provide appropriate care for those arrested with dementia as well as those who develop dementia while incarcerated.

<sup>4</sup>2022 *Alzheimer's disease facts and figures*, <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12638> [<https://perma.cc/ELX3-GB4Z>] (last visited Oct 7, 2022).

<sup>5</sup>*Id.*

<sup>6</sup>Adam Boxer et al., *The Advancing Research and Treatment in Frontotemporal Lobar Degeneration (ARTFL) North American Rare Disease Clinical Research Consortium: Progress and Participant Characterization (S2.008)*, 90 *NEUROLOGY* (2018), [https://n.neurology.org/content/90/15\\_Supplement/S2.008](https://n.neurology.org/content/90/15_Supplement/S2.008) [<https://perma.cc/NLW2-62AM>] (last visited Sep 25, 2020).

<sup>7</sup>Madeleine Liljegren et al., *Criminal Behavior in Frontotemporal Dementia and Alzheimer Disease*, 72 *JAMA NEUROL.* 295 (2015).

<sup>8</sup>*Persons Living with Dementia and the Criminal Justice System*, AM. BAR. ASSOC., [https://www.americanbar.org/groups/senior\\_lawyers/publications/voice\\_of\\_experience/2022/may-2022/persons-living-with-dementia-and-the-criminal-justice-system/](https://www.americanbar.org/groups/senior_lawyers/publications/voice_of_experience/2022/may-2022/persons-living-with-dementia-and-the-criminal-justice-system/) [<https://perma.cc/H7BL-FXSH>] (last visited Jan 16, 2023).

<sup>9</sup>Josiah D. Rich et al., *How Health Care Reform Can Transform The Health Of Criminal Justice-Involved Individuals*, 33 *HEALTH AFF. (MILLWOOD)* 462 (2014).

## Methods

We conducted qualitative semi-structured interviews with legal professionals who have experience in the criminal justice system. We identified eligible participants using social media posts (e.g., Facebook and Twitter) to identify individuals within our professional networks who met eligibility criteria. The social media posts requested names and email addresses. We sent email invites to potential participants who expressed interest and confirmed eligibility prior to scheduling interviews. We also implemented snowball sampling to obtain additional names and contact information for candidates eligible for the study.<sup>10</sup> We ceased recruitment upon meeting data saturation (i.e., no additional themes emerged during interviews). We used a semi-structured interview guide that included three domains: (1) questions pertaining to participants' individual professional experience, (2) issue spotting to elicit potential challenges associated with managing PLWD within the criminal justice system, and (3) questions seeking participants' recommendations for improving treatment and management of persons living with dementia within the criminal justice system. Two investigators (JA, AT) conducted interviews with participants between December 2020 and May 2021. All interviews were recorded and transcribed for analysis. Participants received a demographic survey using RedCap to complete prior to the interview. We used qualitative data analysis, the Framework Method,<sup>11</sup> to evaluate the transcribed interviews within NVivo (a qualitative analysis software program). This includes an inductive coding of transcripts to develop a codebook, which is then applied to all interview transcripts. Two investigators (JA, LM) coded all transcripts using the codebook, with each transcript being reviewed twice (once by each coding investigator).

The team (JA, AT, LM) then charted the data for each relevant code (e.g., dementia detection, placement, training/experience) to allow for comparison of sub-themes across participants. This helped us identify any variations in participants' reports of their experiences and perspectives. The University of California – San Francisco Institutional Review Board approved the study. Additionally, our team conducted regular literature reviews to guide our interpretation of the qualitative data.

## Results

We conducted interviews with fifteen legal professionals, all of whom had experience within the criminal justice system. Of the fifteen participants we interviewed, twelve completed the demographic survey (Table 1). Our analysis of the interviews indicates that the three participants who did not complete the demographic survey did not meaningfully differ from the other participants. However, one participant from Colorado reported unique resources available that may be relevant to assist PLWD who are justice-

**Table 1.** Demographic Results of Participants

| GENDER | AGE RANGES | CURRENT ROLE | YEARS OF LEGAL PRACTICE |                       |   |       |   |
|--------|------------|--------------|-------------------------|-----------------------|---|-------|---|
| Female | 9          | 30–39        | 6                       | State Prosecutor      | 1 | <10   | 3 |
| Male   | 3          | 40–49        | 3                       | State Public Defender | 6 | 10–20 | 7 |
|        |            | 50–59        | 3                       | Private Practice      | 1 | >20   | 7 |
|        |            |              |                         | Other                 | 2 |       |   |
|        |            |              |                         | Unanswered            | 2 |       |   |

<sup>10</sup>Ilker Etikan, *Sampling and Sampling Methods*, 5 BIOM. BIostat. INT. J. (2017), <https://medcraveonline.com/BBIJ/sampling-and-sampling-methods.html> [<https://perma.cc/3CWR-JT67>] (last visited Dec 29, 2021).

<sup>11</sup>Nicola K. Gale et al., *Using the framework method for the analysis of qualitative data in multi-disciplinary health research*, 13 BMC MED. RES. METHODOL. 117 (2013).

involved. We note this in the results where relevant. Participants practiced law within nine different states (California, Colorado, Georgia, Minnesota, Maryland, New Jersey, New York, Texas, and Washington) with between 5-33 years of legal experience. Among those who completed the demographic survey, 9 participants were female. Approximately half of the participants were currently public defenders, with the remaining participants in other roles including prosecutors, private practice, and “other”. The data reflect participants’ experiences and views on the management of PLWD who are justice-involved, with a significant emphasis on challenges that emerge post-arrest.

### *Detecting Dementia*

A *prima facie* barrier to appropriate management of PLWD within the criminal justice system is identifying individuals with dementia or dementia-related cognitive impairment. Participants in this study consistently reported a lack of systematic screenings that would occur if an older adult was arrested, with few exceptions. Among the fifteen participants interviewed, only one referred to a type of screening (e.g., a pre-trial release screening in Colorado) that could potentially detect dementia or cognitive impairment. Our participants referenced three general ways that dementia might be detected. First, an attorney, generally the defense attorney, may become aware of cognitive impairment through interviews. Second, the family reports it to the defense attorney or other person in the system. Third, the police recognize and document impairments at the time of the arrest. Of note, participants reported experiences or insights on dementia detection among individuals after arrest. Among those whom we interviewed, none of the participants had experience or an understanding of how dementia might be detected if an individual became symptomatic while in custody.

Participants consistently reported that dementia may be detected if the attorney became aware of signs that the individual was experiencing cognitive impairment. Generally, this was described as an inability to “track” a conversation or provide meaningful information to assist with the defense. Additionally, some participants reported gaps in memory that raised suspicions.

*Yeah. I think when it's going to become most apparent is when clients don't retain information that we've given them, the short-term memory. [...] And a lot of clients are upset when they don't retain information very well the first time anyway because they're upset. But after multiple discussions and people still not really understanding the basics of what we've been over, that would be a clue that there's a developmental delay or dementia. And that's probably how that would raise the suspicions.*

Participants reported flaws in relying on defense or prosecutors to detect issues associated with dementia or cognitive impairment. For example, detecting dementia via an attorney report relies on the attorney’s prior understanding or knowledge of dementia and the time the attorney spent with the individual to be able to detect signs of impairment.

Participants reported that individuals’ families may also be a mechanism to detect dementia. In this context, the family would raise dementia as a potential cause of the crime to the defense attorney or prosecutor. This was particularly important in circumstances where the legal practitioners involved might not otherwise have detected dementia. For example:

*And she wasn't so old that it would have occurred to me, this is dementia, but I called to speak to her family, and they said, “She has dementia, and we're working on getting help for it. We're working on getting it addressed.” I think it would normally be the family. I mean, I'm guessing we could've eventually figured it out on our own if he would've acted in a certain way. I might've noticed. But in this particular case, I wasn't sure that it was completely legitimate. I actually thought they were going to think that he was malingering [...]*

While only a small subset of participants explicitly referenced examples of family members reporting dementia as a means of identifying it post-arrest. The relevance of family involvement also emerged in

other areas that might be relevant to dementia detection (e.g., see *placement challenges below*). Additionally, in areas where participants report the relevance of family involvement to detect dementia or assure appropriate care for PLWD, the participants recognized the consequences of the system for individuals without family members to advocate for or provide support for the individual.

Some participants reported police as a third way in which dementia might be detected. For example, one participant reported: “*there was some reference to that in the police reports. So the officers on scene clearly would have had some understanding of it which means that the district attorney’s office would have had some awareness based on the reports.*” However, this view on police awareness of dementia at the scene differed significantly from others’ reported experiences. Other participants reported police interpretations of individuals’ behaviors at the time of arrest as “lying” or malingering.

*Well, I mean, to be fair, in cases where law enforcement does an extended interrogation, they should know. And lots of times when you watch those interrogations, it’s painfully obvious that the person has dementia. But the police almost never admit that in any reports or anything. They usually call it lying and say, “Well, he couldn’t give me a good timeline. He couldn’t tell me what happened.” And then you watch the interview and you’re like, “Because he thinks it’s 1967 and doesn’t know what you’re talking about.” But that’s usually characterized by law enforcement as lying or trying to hide things or something like that.*

Expert evaluations of individuals to identify underlying causes of impairment post-arrest emerged as a prevalent theme from interviews, including psychiatric evaluations. There was variation in participants’ reports on the accessibility of expert evaluations, the goals of those evaluations (e.g., diagnostic versus competency evaluation), and the quality of expert opinions. Among those that described the value of expert opinions, two specifically called out access to and the value of social workers who provided insight into individuals’ cognitive status. Additionally, budget and available resources were frequently raised as barriers to accessing experts: “*if you can get an expert witness or even just get medical records and documentation of this person’s history of brain injury, yeah, that would be excellent. I don’t know what the-- I mean, the budget’s going to vary [...]*”. Yet, regardless, the expert evaluations were only available upon request—which means that someone in the criminal justice system would need to determine there was a need for an expert evaluation as the preliminary step.

Participants reported multiple challenges that impeded detecting cognitive impairment or dementia post-arrest. First, multiple participants emphasized that the individual would need to demonstrate severe symptoms for dementia to be detected. Second, participants referenced “masking” (e.g., where the individual covers or hides symptoms) as a barrier to detection.

*Because typically, a lot of the folks that I end up dealing with that definitely have dementia but were still out in the community sort of unsupervised or untaken care of are pretty good at that sort of covering or confabulation to hide the fact that they don’t know what’s going on.*

Finally, given perceived “motivations” to lie about cognitive impairment that could lead to reduced criminal liability for the individual, participants reported the perception that an individual might be malingering (e.g., feigning symptoms or lying). For example, one participant reported: “*Objective diagnoses are one thing, but more subjective ones, that can be faked. If there’s an opportunity to do so, prisoners will often take advantage of it.*” These barriers could impede the accurate detection of dementia or cognitive impairment that could be relevant to PLWD receiving needed care while engaging with the criminal justice system.

### **Placement Challenges**

Placement (e.g., housing) was consistently raised as a barrier to appropriately caring for PLWD who are justice-involved. Participants raised this barrier in the context of offering pre-trial release, alternatives to

sentencing, and release from incarceration post-sentencing. While subtle differences emerged regarding each of those points within the process, the same general themes emerged, including the inappropriate nature of jail or prison for PLWD, limitations on community placement (e.g., with family members), barriers to placement in long-term care residential facilities, and concerns regarding hospitalizations.

Participants consistently recognized that jail or prison was an inappropriate placement for PLWD during pre-trial processes or as sentencing if found criminally liable. Participants reported that jail or custody placement could negatively affect the individual's well-being.

*[A] real struggle when an individual is in jail and doesn't know why and can't remember why, doesn't remember where they are. Obviously, the effects of dementia are disorienting in the best of situations, but it just compounds that whole issue when they're in jail. Also, obviously, in jail they're not receiving the type of medical attention and treatment that they would otherwise be receiving out.*

Other participants raised concerns that jail and prison facilities are ill-suited for older adults experiencing cognitive and physical disabilities as well as that correctional staff are not sufficiently trained to support the needs of older adults, particularly those who experience cognitive deficits.

*Well, for the more serious cases, the ones that I'm talking about where there's either been a serious injury or loss of life, one of the most difficult things is housing. I mean, if you can imagine placing an 80-plus-year-old individual who's in frail health physically and mentally in an ultra-sterilized jail environment that's not always safe, that's huge. A classic example in our jails, if you are on any of the standard floors, in order to get to an attorney visit booth, you have to climb two flights of stairs, you have to do it on you're own, and you have to know where you're going. We have seen circumstances in which the individual can't figure out how to get from their cell door to the attorney visit booth because it's just beyond their abilities. I would say that our jails, and I'm speaking primarily in [jurisdiction], both of our jails simply have not been designed, and our staffs have not been trained-- by that, I mean the sheriff's staffs have not been trained in order to understand, identify, and alleviate some of the issues there.*

In the context of pre-trial release, individual circumstances might result in extended jail holdings.

*[W]hat usually happens is that the individual languishes in custody under incredibly unsafe circumstances for somebody with [inaudible]. And such a way and circumstances certainly exacerbate all of the consequences of being somebody with dementia, in terms of the anxiety and agitation and all of that.*

Participants acknowledged that PLWD are unlikely to have the financial or community resources to secure bail. Yet, alternatives to being held in custody during pre-trial procedures were not consistently described, and some appeared to be dependent on subjective characteristics of judicial decision-making (e.g., sympathetic judges). For example, a PLWD might be released to the community if a family member comes forward to care for the individual. One participant raised the cost of caring for a person with dementia as a driver for pre-trial release. Yet, these examples were reported by individual participants without reference to general policies or procedures in their jurisdictions.

Alternatives to jail or prison placement were limited by the availability of alternative options. Underlying these challenges was a tension between safety for others and the individual, versus appropriate care for a PLWD.

*This is sort of a systemic issue that obviously expands far beyond this issue, beyond this narrow question - but there's a question of what to do with someone who has Alzheimer's type dementia that manifests itself in physical aggressiveness toward other residents and care providers. They need a place to live, and memory care memory-- care facilities would seem to be better than the alternatives. But*

*the tension is that if they present a clear and present danger to staff and residents, what to do with them and how to deal with that. [...] One thing is you definitely need to have enough staff. You need to make sure they're properly medicated and things like that. And a lot of times these facilities are understaffed, and they just don't have the capacity or the bandwidth to do it [...]*<sup>12</sup>

Community placement was used in our data to describe housing or placement in a non-institutional setting (e.g., returning home or living with a family member). Participants reported multiple factors that limit whether a PLWD could be placed in the community. First, an individual must have a family member to provide care or support if they are deemed unsafe to live alone. In the context of a pre-trial release, these issues are particularly challenging if a PLWD lives alone. For example, *"there's no way you're going to be able to talk to them about their case. They can't manage that. You need to be able to set them up with a phone with services, with someone who checks on them."* Second, they must be safe to return home. And third, based on the charged offense and the status of their case, they must be eligible to return home. These limitations, per participants' reports, hindered the ability of using community placements as genuine options for PLWD who were justice-involved during pre-trial, as alternatives to sentencing, or post-conviction.

Long-term care residential settings (e.g., assisted living, nursing homes, skilled nursing facilities) are institutional settings designed to support residents with their activities of daily living and differ based on need. Participants recognized long-term care residential settings as an appropriate alternative where individuals might obtain the care needed, and yet recognized critical limitations on placing individuals who are justice-involved within these settings. First, if an individual poses a risk to other residents, it may be difficult to find a placement where safety measures can be assured.

*Yes, I think so. He resided with his wife in the community. He murdered her. So he doesn't really have anywhere to go. He has two adult daughters, and they both want him to be able to be in a care unit because that's where he should have been beforehand anyway. So it will be just a process of trying to get him out of the state hospital and into a privately-- perhaps for his case, because he has some retirement funds and things like that, private-funded memory care unit. However, because he's going to be committed on the basis of having committed a felony, it's going to be extremely difficult to ever get him out of the hospital because you have to prove that he's no longer at risk of committing similar acts, which is almost impossible to prove to the court. So he'll probably die in the state hospital.*

Second, residential facility policies may block the admission of an individual who has any criminal record, particularly a record of violence or sexual crimes.

*And because they're privately owned, they can't be mandated to take any particular client, so they can turn them down. So, if they see a client that has a criminal history or has a substance abuse history or things like that, they just say no. So the state approves the person and says, "Yes, you're eligible for this service that you obviously and desperately need." And then they also say, "But we can't force anyone to give it to you."*

*I think that really comes down to the individual facility's policies. Yeah, I'd have to say-- because I don't think that there's any- or I'm not aware of- it's certainly not my expertise - any state regulations regarding sex offenders in any kind [...]*

And third, residential facilities might be cost-prohibitive if a PLWD lacks resources or familial support. For example, *"I was talking about getting into care facilities and things like that. If you don't have any family contacts and they don't remember their family, that's that much more difficult."*

<sup>12</sup>The use of medication should only be used as a last resort for the safety of a patient. The inappropriate use of chemical restraints on the elderly is still an ongoing legal and ethical challenge.

Participants reported hospitalizations, particularly in psychiatric or mental illness hospitals, to be consistently used as alternatives to jail or sentencing for PLWD. However, participants also recognized that hospitalization in psychiatric medical care facilities is inappropriate. This was highlighted in the context of pre-trial use of placement as an effort to restore competency.

*I think structurally there is a flaw. I think that treating them as ordinary criminals because their actions constitute criminal behavior really doesn't take into account who that person-- the underlying issues of that person and who that person is and the reasons why we punish people as a society. There's no deterrent effect for a dementia patient. There's no rehabilitation for dementia. We cannot simply cure their dementia and then punish them and they go, "Oh, God, sure, now I'll never shoplift."*

Additionally, participants reported cost and safety barriers to accessing hospital services for PLWD at multiple stages of the criminal process. This included limited availability of hospital beds, resulting in longer time in custody (e.g., jail).

Ultimately, participants consistently recognized a lack of viable placement options as a critical limitation of appropriately caring for PLWD who are justice-involved.

*Yeah. Well, the huge barrier is the lack of options. And well, that's the biggest barrier that I would state first is that when people are transitioning out of prolonged detention, either in an incarceration setting or in some kind of a medical setting with great controls, there just aren't enough alternatives in the community. And so inappropriate placements tend to be utilized. So that's a huge barrier.*

This sentiment was consistent with participants who proposed a need for special housing tailored to PLWD that could provide appropriate care. For example, one participant referenced special housing units within prisons in New York and Connecticut that are designed for PLWD and other age-associated disabilities. Another participant recommended housing that resembled long-term care residential facilities:

*I mean, I feel like-- I feel like it wouldn't have to look that much different than the memory care units in assisted-living facilities. I mean, you can't leave those facilities. They're all alarmed, and you can't-- you're not allowed to do that. And I think with the proper staffing and the proper identification of the different-- and, of course, this is all on gradations. I mean, I'm sure there's homicidal individuals who have dementia or who become homicidal because of their dementia, but that, in my opinion, would probably be a very, very small percentage of all of the individuals who have dementia or Alzheimer's and commit crimes. I'm sure that that is a minuscule part of that. [...] And memory care units have special features, including-- like I say, they're locked down, but they have people who are supposed to be trained in working with people who have dementia, which to me-- I mean, a lot of this can be dealt with if-- I find that there is a huge disparity in the ability of demented individuals to do well based on the amount of attention and knowledge people have relating to the condition.*

### Overarching Themes

While dementia detection and placement emerged as linchpin issues to appropriate care for PLWD who are justice-involved, two additional overarching themes emerged as relevant across the data. First, training and experience related to dementia within the criminal justice context. Second, recommendations for improved policies and systems.

#### Training and Experience

Training and experience of criminal justice system professionals (attorneys, judges, police, correctional officers) emerged throughout the data as a factor that affected or related to barriers to care for



PLWD. Participants reported a lack of formal training (e.g., continuing legal education) relevant to dementia and/or cognitive impairment within the criminal justice system. The exception to this was a reference to continuing legal education on mental illness. However, details of that continued legal education session were not described to provide insight into its relevance to dementia. Many participants reported that their awareness of dementia, including related symptoms, stemmed from personal or familial experience, prior exposure to dementia through other education (e.g., studied dementia-related topics during undergraduate studies), or professional experience. Participants reported the gap in education and training on dementia as a barrier to effectively counseling or caring for PLWD who are justice-involved.

*So, it's all about educating, and it's all of the players in the court system in and around the court system. So that's the biggest barrier. Another barrier is lack of, and this is why I was happy to join you all in this project, lack of data, lack of information about how dementia presents relative to how mental illness presents, from which people can really even educate themselves. [...] And that becomes really important because the failure to have that data means that policymakers who'd be looking to shape and change the policy about these things don't have good evidence that lawmakers, if you will, are looking for to make systemic change. And that's a real problem.*

The issue of education and training relevant to dementia within the criminal justice system emerged consistently as a factor affecting detection, placement options (e.g., whether the correction officers were trained to manage dementia, and sentencing (e.g., judicial understanding)). Participants also referenced training as a recommendation to improve the system.

### *Recommendations*

Participants recommended a broad variety of changes to address the issue of PLWD in the criminal justice system. Their recommendations included structural changes to the legal system, training for people in the legal system who interact with PLWD, and increased resources and housing options for PLWD both within the legal system and in the community. Embedded within the recommendations were sentiments that PLWD are different from other people post-arrest. Included as an underlying agreement that PLWD should not be subject to the same punitive measures of the criminal justice system, “*I simply do not believe people who are incapable of forming the mental intent that we require under the law deserve to be punished. Period. I don't care what they do.*” To remedy this, respondents identified the need for an exemption to a required restoration before trial, diversion courts structured after the drug or mental health courts, and plea options specifically designed to acknowledge the limited capacity of PLWD.

Participants acknowledged a need for training and education about dementia for all people involved in the justice system, ranging from law enforcement to guards to judges and prosecutors. They explicitly acknowledged that there was no required training on dementia or geriatrics provided in law school or during continuing education and believed that training, awareness, and understanding of dementia could prevent PLWD from being unjustly incarcerated.

*More training. We don't see a ton of these like I said. They come in maybe once a year. And in almost every circumstance, they're domestic violence-related because that's the individual that's home with the person. I would like to see our team get a little more training on the issue of dementia and dementia-related issues.*

In addition to these suggestions, participants widely recommended a need for more social services and placement options for PLWD within the legal system and the community. Within the legal system, they identified the need for psych examiners who were specifically trained to work with the elderly and safe housing and placement for PLWD for people who have been arrested and awaiting trial as well as

those who develop dementia during long-term incarceration was identified as an issue. Possible solutions to these issues were things like assigning a social worker to PLWD pending trial to assist them with housing and age-specific facilities modeled after assisted living or memory care. Additional community housing and social workers to assist PLWD were named as both ways to prevent a PLWD from entering the justice system as well to safely transition PLWD from incarceration to the community.

*And you have to be able to identify those people that need the help and need the community's support and be able to get that community support for them. Now, with dementia patients, especially, we need to make sure that they have someone who is looking out for them, who is going to make sure that this doesn't get to be a worse problem, and make sure also that they are safe.*

## Discussion and Conclusions

Using semi-structured interviews with legal professionals, this study found that two critical barriers would impede the appropriate care of PLWD who are justice-involved, including challenges detecting dementia among individuals who are justice-involved and lack of placement options. Underlying these two barriers, participants reported a lack of training or education regarding dementia or cognitive impairment. Consistent with this, participants recommended a need for resources within the community to prevent incidents, during or within the criminal justice system, and for alternative options to pre-trial holds and sentencing.

Our results are consistent with prior literature emphasizing emerging challenges affecting older adults who are justice-involved. In particular, the recently completed American Bar Association survey on "Persons Living with Dementia in the Criminal Legal System" highlighted similar concerns regarding placement.<sup>13</sup> Survey respondents of that study reported a wide variation in resources available for incarcerated PLWD, ranging from assisted living to nothing at all. When asked for recommendations, roughly one out of three of respondents stated that training and placement resources would improve their ability to address dementia cases. These respondents reported that the health care and legal resources available to PLWD post-arrest are not appropriate for this population. The report recommends improved community resources for PLWD, increased resources and support for public defenders, improved professional training, and science-based practice guidelines for defendants and incarcerated PLWD.<sup>14</sup>

Policy and systematic changes are needed to appropriately tailor existing services and processes to PLWD who are justice-involved. Our results emphasize the need to develop a screening mechanism to effectively identify individuals experiencing cognitive impairment and dementia at the time of an arrest. This is a necessary first step in diverting individuals from the standard criminal justice process to a system that provides care and services consistent with their needs. Additionally, while there are diversion programs and alternatives to sentencing for juveniles and individuals with psychiatric illness, there is a lack of similar options for people living with dementia.<sup>15</sup> PLWD, when identified, are generally subjected to the same systems, processes, and policies as individuals with psychiatric illnesses. Participants in our study emphasized that psychiatric services and policies are ill-suited for individuals with dementia in part because psychiatric services and policies focus on rehabilitation through treatment. Dementia is a progressive illness and not reversible, thus PLWD cannot benefit from treatment aimed at "rehabilitating." We did not evaluate data from our study examining the application of affirmative defenses (e.g., not guilty by reason of insanity) and other mechanisms to reduce criminal liability (e.g.,

<sup>13</sup>*Persons Living with Dementia and the Criminal Justice System*, *supra* note 8.

<sup>14</sup>*Id.*

<sup>15</sup>Jalayne J. Arias & Lauren S. Flicker, *A Matter of Intent: A Social Obligation to Improve Criminal Procedures for Individuals with Dementia*, 48 J. LAW MED. ETHICS J. AM. SOC. LAW MED. ETHICS 318 (2020).

competency determinations) in this article. However, much like the data reported here, the criminal justice system has “lumped” dementia and dementia-related cognitive impairment with psychiatric illnesses. This leads to inappropriate placement and care of PLWD and worsens outcomes for this population. Policies and procedures used to prevent criminal justice interactions, provide diversion programs, and offer alternative sentencing solutions may, however, offer a preliminary model for new approaches to PLWD who are justice-involved.

The Sequential Intercept Model (SIM) uses public health approaches to mitigate the criminalization of psychiatric illnesses.<sup>16</sup> The model aims to provide for and integrate community and social services through the criminal justice system.<sup>17</sup> This includes providing services to individuals with psychiatric illnesses that could reduce their risk for criminal justice interactions. This model has also been successfully used to prevent criminal justice interfaces and negative outcomes among veterans.<sup>18</sup> SIM serves as the ideal conceptual model to guide policymaking aimed at providing community and social resources tailored to individuals with dementia. This is consistent with participants’ recommendations in this study to improve resources at all stages, including assuring care to PLWD in the community whose symptoms and behaviors pose a risk for criminal actions. Future research should begin to explore the potential impact of community resources among PLWD. It is important that this research is aligned with the SIM and includes criminal justice interactions as outcome measures.

This study includes limitations that prevent it from establishing generalizable results to describe legal practices and/or policies for PLWD. First, the study uses qualitative approaches to collect and describe legal practitioners’ experiences and perspectives, to establish generalizable data that reflects practices quantitative approaches (e.g., surveys) would be needed that collect data across all fifty states. The cohort of research participants in this study may be biased in two ways. A majority of interviewed participants represent defendants/accused. This may bias results towards defense policies and perspectives. Additionally, the interview participants lacked racial and ethnic diversity. Future studies should aim to recruit diverse participants. In this qualitative study, we did not determine that the lack of diversity affected the results. Despite these limitations, the study achieved its broader goal and collected narratives from key stakeholders that provide unique insight into the lived experience of those working in the system. These narratives provide hypothesis-generating data that can be used to test theories and develop interventional studies to provide for evidence-based policies.

Aging in the criminal justice system has been largely understudied. Emerging data is powerful in demonstrating a need to do better. Data that quantify rates of dementia among older adults at the time of arrest and health-related outcomes for PLWD subjected to the criminal justice system is critical to the next steps. These data can inform the best use of resources and how to best design screening programs and develop appropriate placement options. These efforts will take a significant amount of time to develop and implement. Another need emphasized in our data is the gap in training for criminal justice professionals on dementia. Developing training (e.g., continuing legal education) aimed at dementia in the criminal justice system could have a more immediate impact on improving care and management of PLWD who are justice-involved.

PLWD are uniquely at risk for criminal justice interactions. The unique characteristics of dementia pose novel challenges to the system. A critical examination of the entire system using public health principles that consider the special needs of older adults, particularly those with cognitive impairment, is critically needed.

<sup>16</sup>Mark R. Munetz & Patricia A. Griffin, *Use of the Sequential Intercept Model as an Approach to Decriminalization of People With Serious Mental Illness*, 57 *PSYCHIATR. SERV.* 6 (2006).

<sup>17</sup>*Id.*

<sup>18</sup>Jessica H. Blue-Howells et al., *The U.S. Department of Veterans Affairs Veterans Justice Programs and the sequential intercept model: Case examples in national dissemination of intervention for justice-involved veterans.*, 10 *PSYCHOL. SERV.* 48 (20120827).

**Jalayne J. Arias** is an Associate Professor in Health Policy & Behavioral Sciences in the School of Public Health at Georgia State University. Prof. Arias' research focuses on the policy, legal, and ethical questions that arise in Alzheimer's disease and related dementias, aging, and neurosciences. Professor Arias is a multidisciplinary researcher and scholar leading studies at the intersection of science, health care, policy, and law. Her research portfolio addresses critical policy, social, legal, and ethical challenges for older adults and neurosciences. Her prior and ongoing studies have identified employment and insurance discrimination based on emerging techniques to identify risk for Alzheimer's disease, evaluated genetic data-sharing guidelines in research, considered the relevance of return of research results for recruitment and enrollment, analyzed private payers' coverage policies for genetic testing, examined challenges to financing long-term care, identified policy needs within the criminal justice system in managing and caring for older adults, and characterized financial and legal decision-making in young-onset dementias. Her research has been funded by the National Institutes of Health, including a K01 Career Development. She has also received funding through foundation grants and non-profits including the Alzheimer's Associate, the Marcus Family Foundation, the Hellman Family Foundation, and the Aging Research in Criminal Health Network.

**Lillian Morgado** is a research assistant at Georgia State University's School of Public Health. Lillian's work address ethical and policy issues affecting older adults. She received a master's degree in public health from the Georgia State University School of Public Health in 2023 and a bachelor's degree in geography from the University of Georgia in 2015. She is interested in health policy, aging adults, and health inequities.

**Ana M. Tyler**, JD, MA, received her undergraduate degree from The Ohio State University and her law degree with a concentration in health law and policy and master's degree in bioethics from Case Western Reserve University. After completing a fellowship in Clinical Ethics from Sutter Health (California Pacific Medical Center, San Francisco), she worked as a clinical ethicist at Beaumont Health (now Corewell Health) in the metro Detroit, Michigan area. Ana is a program manager at the Memory and Aging Center at the University of California San Francisco and works in the Yokoyama Lab on genetic data-sharing initiatives and in research examining legal, ethical, policy and social issues relating to genetic data sharing and predictive testing for neurodegenerative illnesses.