

## A Scoping Review of Ethical and Legal Issues in Behavioural Variant Frontotemporal Dementia

Anirudh Nair, Colleen M. Berryessa and Veljko Dubljević

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### Article abstract

Behavioural variant frontotemporal dementia (bvFTD) is a subtype of frontotemporal dementia characterized by changes in personality, social behaviour, and cognition. Although neural abnormalities cause bvFTD patients to struggle with inhibiting problematic behaviour, they are generally considered fully autonomous individuals. Subsequently, bvFTD patients demonstrate understanding of right and wrong but are unable to act in accordance with moral norms. To investigate the ethical, legal, and social issues associated with bvFTD, we conducted a scoping review of academic literature with inclusion & exclusion criteria and codes derived from our prior work. Among our final sample of fifty-six articles, four mentioned bvFTD patient-offenders as unfit to stand trial by insanity, and sixteen mentioned the use of dementia evidence in a court of law to better understand the autonomy of bvFTD patients. Additional emergent issues that were discovered include: training police officers to handle situations involving bvFTD patients and educating healthcare providers on how to help caregivers navigate bvFTD. The current literature highlights the inadequacy of traditional applications of medico-legal categories such as autonomy, capacity and competence, in informing cognitive capacity assessments in clinical and legal settings and deserves consideration by neuroethicists.



ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

# A Scoping Review of Ethical and Legal Issues in Behavioural Variant Frontotemporal Dementia

Anirudh Nair<sup>a</sup>, Colleen M. Berryessa<sup>b</sup>, Veljko Dubljević<sup>c</sup>

## Résumé

La variante comportementale de la démence frontotemporale (vcDFT) est un sous-type de démence frontotemporale caractérisé par des changements de la personnalité, du comportement social et de la cognition. Bien que les anomalies neurales fassent que les patients atteints de vcDFT aient du mal à inhiber les comportements problématiques, ils sont généralement considérés comme des individus totalement autonomes. Par la suite, les patients atteints de vcDFT démontrent une compréhension du bien et du mal, mais sont incapables d'agir conformément aux normes morales. Afin d'étudier les questions éthiques, juridiques et sociales associées au vcDFT, nous avons procédé à une revue de la littérature académique avec des critères d'inclusion et d'exclusion et des codes dérivés de nos travaux antérieurs. Parmi notre échantillon final de cinquante-six articles, quatre mentionnent les patients atteints de vcDFT comme inaptes à être jugés pour cause de folie, et seize mentionnent l'utilisation de preuves de démence dans un tribunal pour mieux comprendre l'autonomie des patients atteints de vcDFT. D'autres questions émergentes ont été découvertes, notamment la formation des policiers aux situations impliquant des patients atteints de vcDFT et l'éducation des prestataires de soins de santé sur la manière d'aider les soignants à faire face à la vcDFT. La littérature actuelle met en évidence l'inadéquation des applications traditionnelles des catégories médico-légales telles que l'autonomie, la capacité et la compétence, pour informer les évaluations de la capacité cognitive dans les contextes cliniques et juridiques, et mérite d'être prise en compte par les neuroéthiciens.

## Mots-clés

prise de décision, démence frontotemporale, maladie neurodégénérative, neuroéthique, questions réglementaires

## Abstract

Behavioural variant frontotemporal dementia (bvFTD) is a subtype of frontotemporal dementia characterized by changes in personality, social behaviour, and cognition. Although neural abnormalities cause bvFTD patients to struggle with inhibiting problematic behaviour, they are generally considered fully autonomous individuals. Subsequently, bvFTD patients demonstrate understanding of right and wrong but are unable to act in accordance with moral norms. To investigate the ethical, legal, and social issues associated with bvFTD, we conducted a scoping review of academic literature with inclusion & exclusion criteria and codes derived from our prior work. Among our final sample of fifty-six articles, four mentioned bvFTD patient-offenders as unfit to stand trial by insanity, and sixteen mentioned the use of dementia evidence in a court of law to better understand the autonomy of bvFTD patients. Additional emergent issues that were discovered include: training police officers to handle situations involving bvFTD patients and educating healthcare providers on how to help caregivers navigate bvFTD. The current literature highlights the inadequacy of traditional applications of medico-legal categories such as autonomy, capacity and competence, in informing cognitive capacity assessments in clinical and legal settings and deserves consideration by neuroethicists.

## Keywords

decision-making, frontotemporal dementia, neurodegenerative disease, neuroethics, regulatory issues

## Affiliations

<sup>a</sup> Icahn School of Medicine at Mount Sinai, New York, New York, USA

<sup>b</sup> School of Criminal Justice, Rutgers University, Newark, New Jersey, USA

<sup>c</sup> Department of Philosophy and Religious Studies, North Carolina State University, Raleigh, North Carolina, USA

**Correspondance / Correspondence:** Veljko Dubljević, [veljko\\_dubljevic@ncsu.edu](mailto:veljko_dubljevic@ncsu.edu)

## INTRODUCTION

Behavioural variant frontotemporal dementia (bvFTD) is a subtype of frontotemporal dementia characterized by changes in personality, social behaviour, and cognition (1). Patients with bvFTD often behave in inappropriate or illegal ways, engaging in impulsive behaviour or committing crimes, as seen in 37-56% of reported cases (2). Despite the fact that they may lack the neural circuitry to inhibit wrong actions, patients with bvFTD are generally considered fully autonomous individuals (3). This confusion about autonomy may stem from the seemingly paradoxical ability of bvFTD patients to know the difference from right and wrong yet not be able to act in accordance with their understanding of moral norms (4). Unsurprisingly, the condition is linked with a range of ethical and legal issues.

## Ethical Issues in bvFTD

Dementia, and especially bvFTD, reverses the hard-won freedoms and rights that are enjoyed by most adult human beings (5). Social exclusion and stigmatization of both persons living with dementia and their family members contribute to significant mental health burdens. Additional crucial ethical concerns raised by ethicists are deception, objectification, social isolation, and marginalization (6). However, the range of concerns may seem daunting unless a form of classification is adopted. A common way that academic debates approach ethical issues (in any type of condition) is to apply principlism. Principlism is

an established approach in biomedical ethics, based on a set of values that medical professionals can refer to in the case of confusion or conflict, which include 1) respect for autonomy, 2) beneficence, 3) non-maleficence, and 4) justice (7).

Respect for *autonomy* refers to the right of the competent individual to make personal decisions regarding their medical care, including the right to refuse unwanted treatment. The principles of *beneficence* (do good) and *non-maleficence* (do no harm) originate from the earliest versions of the Hippocratic Oath. Today, these elements guide healthcare professionals in their administration of medical interventions: all other things being equal, the morally right medical intervention will be the one that is most beneficial to the patient and least harmful. While beneficence and nonmaleficence are presented in foundational bioethics texts as separate principles, they jointly operate as a dyad in clinical practice and research. Finally, the principle of *justice* – usually pertaining to the degree to which healthcare resources are fairly distributed in society – is to some extent dictated by the economic environment in which a medical system operates. Notions and theories of justice vary widely across academic and political fields, and we will limit our discussion to the specific cases of injustice as they pertain to living with dementia, while at the same time noting that, at least in the US, socioeconomic status often determines the degree to which, if at all, healthcare resources are accessible (8).

The principlist answer to questions of autonomy in bvFTD suffers from a kind of dichotomy, as noted above: morally, the patients seem to be lacking autonomy, whereas legally, they are considered fully autonomous. This dichotomy mirrors the debate on autonomy in dementia more generally. Two well-established positions about autonomy in dementia, developed by Ronald Dworkin and Agnieszka Jaworska respectively, offer guidance in the pressing ethical dilemmas.

Ronald Dworkin (9) argues that there are two types of interests: *critical* and *experiential*. Critical interests are those relating to what an individual considers good or bad and are fundamental to a person. Experiential interests are those relating to one's immediate experiences: one's interest in experiencing pleasure, avoiding pain, etc. According to Dworkin, persons in the late stages of dementia are capable of holding on to their experiential interests but lack the agency to express their critical interests.

By contrast, Agnieszka Jaworska (10) defends the view that the immediate interests of an individual, even in cases of dementia, should not be overridden as long as this individual has the ability to value them. She adds that experiential interests are time-specific, for one can only care for them if the person has them currently. Dworkin and Jaworska both agree that dementia patients can experience feelings, and therefore have experiential interests, but disagree on the capacity to hold critical interests. Unlike Dworkin, who believes dementia patients have no critical interests, Jaworska argues that they do, and are just not in a state to communicate them. Dworkin argues that dementia patients have no concept of a whole life, which in turn prevents them from generating critical interests. Jaworska responds by saying one does not need to have the concept of a whole life to generate critical interests; one merely needs to have a concept of what one wants and does not want in one's life. From this she links the ability to generate critical interests to the ability to value things, since the things a person values as good are also the things they want in their life. Further, someone can still have the capacity to value things that are good for them even if they do not remember their history.

The principlist approach to the ethics of FTD considers the issue of justice, particularly the fair distribution of resources. Dementia care is expensive, and most families living with dementia struggle financially. In the US, up to 75% of the care is provided directly by family (11), and in 2013, the value of unpaid caregiving for dementia – approximately \$470 billion – exceeded the value of paid home care and total Medicaid spending in that same year (12). Partly due to effects of stigma, care provided by the family comes at substantial personal cost and risk to their own wellbeing (13).

In addition to economic justice issues, FTD also presents potential social justice issues, especially regarding feminization of care and unfair discrimination. Namely, some feminist literature has addressed the economic and political context of “feminized jobs” such as caregiving (14): these jobs tend to be the least respected and paid in any given society. Additionally, caregiving in the family is usually provided by women. Moreover, the medical community and the media sometimes speak about the impact of dementia in catastrophic terms, such as the “dementia tsunami” which is “worse than death” (15). This “panic-blame framework” (16) conceptualization of dementia is driving dominant representations, contributing to social isolation, stigmatization, and ultimately constraining access to adequate healthcare and support.

## Legal Issues in bvFTD

In recent years, there has also been both recognition and concern about the complex relationship between FTD, particularly bvFTD, and criminal behaviour. In contrast to other forms of dementia, as mentioned above, bvFTD spares memory and learning in its early stages, and instead, its most striking symptoms are impairments to moral decision-making, empathy, punishment and reward processing, and impulse control (2-3,17). As such, this nexus of symptoms leads individuals with bvFTD, specifically in the early stages of the disease, to be at a higher risk of violating moral and legal norms; many such transgressions committed by individuals with bvFTD are criminal, with their likelihood of criminality being significantly more like than those with other forms of dementia (18). Crimes associated with bvFTD are most often reactive rather than instrumental in nature and are the result of the disinhibition, punishment insensitivity, and lack of empathy associated with the disease (19). This, unfortunately, often leads people with bvFTD to increased involvement with the criminal justice system; although the prevalence of bvFTD specifically in the criminal justice system is not known, the prevalence of dementia in US prisoners has been estimated to range from 1% to 30% (20).

Individuals with bvFTD have been considered a significant challenge for the justice system and correctional facilities, raising as they do a range of complex legal issues for the competency or fitness to stand trial, legal insanity, responsibility determination, appropriate sentencing, and how evidence on bvFTD is used in trial proceedings (21). Scholars argue that the current legal framework in the US is oriented more towards stable psychiatric disorders that can be treated, and with symptoms that can improve; conversely, bvFTD, like other forms of dementia, is neurodegenerative and marked by progressive cognitive decline (21). In some cases, by the time an offense is tried, the individual's bvFTD will have progressed significantly from its earlier stages in which the criminal behaviour was committed, which can cause intense complications (22).

Further, scholars have argued that different types of evidence on bvFTD – including neuroimaging data, psychiatric or neuropsychological reports, and genetic testing – may be potentially useful for decision-makers in determinations of competency, responsibility, and degree and type of punishment (19). Indeed, the severe neurological influences of the disease on the risk for criminal behaviour can be hard – for defense attorneys, prosecutors, and judges, who are likely not familiar with the complex effects the disease's symptomatology has on individual decision-making and processing – to both understand and know how to potentially integrate it in legal decision-making (22). Unsurprisingly, there have been widely disparate outcomes in trials in which underlying bvFTD has been either missed, disregarded, or minimized (21). Given the likelihood of increasing cases of this kind, understanding the range of immense legal issues and implications that bvFTD can have for the trial process, and the overall criminal justice system, is necessary in order to efficiently and fairly address and manage criminal behaviour stemming from the disease (19).

The discussion above shows that the ethical and legal issues associated with bvFTD are complex and multifaceted. To map the emerging trends in normative issues of bvFTD, we conducted a scoping review of academic literature found in Web of Science, PubMed, and PhilPapers databases, as these best capture the general sentiment of the larger academic community towards the normative issues facing to bvFTD.

## METHODS

### Data Collection

This project builds upon our prior research regarding the public representation of legal and ethical issues faced by persons with Frontotemporal Dementia (FTD) and their caregivers (23). Thus, our aim in the current study was to ascertain the extent of any similarly relevant discussions in the academic literature. To this end we first searched common, widely accessible databases for any articles relevant to frontotemporal dementia in the aforementioned capacities, and subsequently coded the retrieved articles qualitatively with themes identified by Nair and Dubljević (23).

We first constructed a comprehensive search query that comprised of the following terms: *“theft” or “violations” or “violent” or “violence” or “moral” or “immoral” or “morality” or “immorality” or “criminal” or “illegal” or “wrong” or “ethics” or “justice” or “ethical” or “crime”* and *“frontotemporal dementia”*.

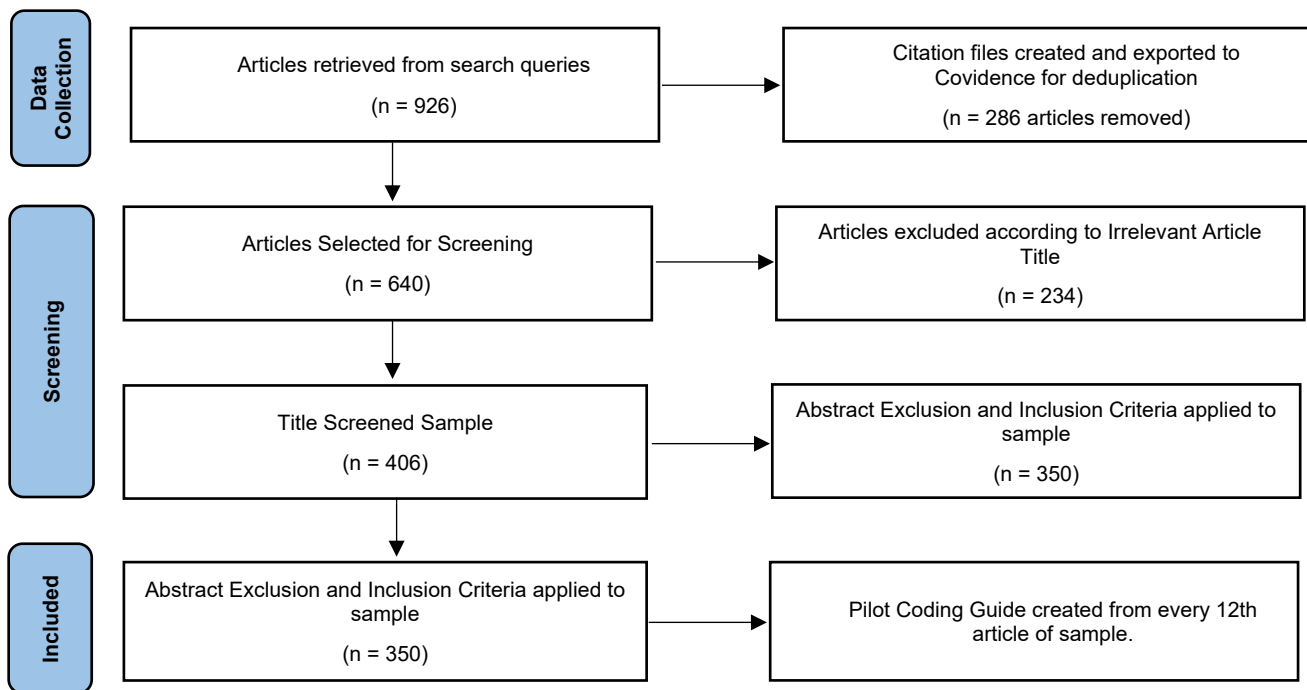
This search query was then submitted to the PubMed and Web of Science databases. We selected these databases in order to retrieve a sample of articles that were wide-ranging in their themes, but also easily accessible, to better reflect how the public domain might be informed. Two coders (AN and a research assistant under the supervision of VD) performed the same search procedure independently. The search was first done using PubMed, with the “full-text” criteria selected and no limits on the date range for the articles, and yielded 194 articles. Next, the same search was conducted in Web of Science, with the “Topics” criteria selected, within the date range of 1950 and 2021 to ensure both coders retrieved the same search results; this search yielded 191 articles.

A similar search was also performed on the PhilPapers database to integrate further articles into our sample that examined FTD from ethical or legal perspectives. This search was performed with the “Professional authors” criteria selected, using the “basic” filter and no limits on the date range. Due to constraints on maximum terms permitted per search, we split the aforementioned search query into individual search terms: *“theft & frontotemporal dementia”, “violations & frontotemporal dementia”, “violent & frontotemporal dementia”, “violence & frontotemporal dementia”, “moral & frontotemporal dementia”, “immoral & frontotemporal dementia”, “morality & frontotemporal dementia”, “immorality & frontotemporal dementia”, “criminal & frontotemporal dementia”, “illegal & frontotemporal dementia”, “wrong & frontotemporal dementia”, “ethics & frontotemporal dementia”, “justice & frontotemporal dementia”, “ethical & frontotemporal dementia”, “crime & frontotemporal dementia”*.

The individual searches collectively yielded 521 articles. The articles in each search were compiled as citation files and exported into Covidence, an online coding platform for literature reviews. Each coder submitted their own searches to Covidence, and duplicates were automatically removed, yielding 640 total articles to be screened.

## Data Screening

Figure 1: Adapted PRISMA flowchart



After duplicates were removed by the program, the two independent coders (AN and the research assistant) screened the sample by title to remove any immediately irrelevant articles. A third coder, VD, resolved any disputes that arose. 234 articles were excluded as irrelevant during the title screening phase.

The sample was then further screened by abstracts according to the criteria in Table 1.

Table 1: Inclusion and exclusion criteria used to screen articles

Inclusion	Exclusion
Ethical Dilemmas	Irrelevant
Crime	Tangential
Decision Making	Duplicates
Ethical and Legal Implications in Relation to FTD	Articles that discuss FTD but not Ethical or Legal Issues
(Peer Reviewed) Articles in English	Articles not in English

Finally, articles were further screened using the above criteria based on their abstracts, which resulted in the removal of a further 350 articles from our total sample, leaving a final sample of 56 articles.

## Data Coding

Next, a smaller pilot sample was constructed from the full sample to assess intercoder reliability and resolve any discrepancies between the coders with regards to the classification of the data, while also revealing any emergent codes that were not already included in the coding scheme. To accomplish this, the articles in the final sample were sorted alphabetically and every 5<sup>th</sup> article selected for review. This yielded a pilot sample of 12 articles, which were subsequently coded by two independent coders (AN and the research assistant). After conducting the pilot sample review, the exclusion criteria from Table 1 were applied to each individual article in the full sample. The remaining articles were subsequently fully coded.

Each of the codes were grouped into three thematically similar domains, and each code was then further categorized into sub-codes to capture the range of incidence of each. The domains, codes and subsequent sub-codes are listed below along with the basis used for their classification.

### 1. Pathology and Quality of Life

This domain aimed to capture the incidence of dementia in the literature, along with any discussions on quality of life for both patients with FTD as well as their caregivers. The codes in this domain are as follows.

### Type of Pathology

All of the studies in our sample were included based on their discussion of frontotemporal dementia. Although a majority of the literature explicitly tested for this behaviour, many studies also categorized any behaviour that was a consequence of frontal lobe deterioration as *frontotemporal dementia* (FTD). We were also interested in identifying the number of instances where FTD was further classified as *behavioural variant frontotemporal dementia* (bvFTD).

### Recommendations

For this code we identify any recommendations on how best to deal with the disease, suggested lifestyle choices for preventing or lessening the risk of disease, or strategies for managing the disease and its symptoms that were recommended for both *persons with dementia*, as well as their *caregivers*. We also included any recommendations mentioned in the literature for *healthcare providers*. This included personnel that were involved in any capacity in the diagnosis or treatment of the disease.

### Stigma

Here we identified any mention of sources of stigma or feelings of shame that were associated with the disease and its behaviour. These included:

- **Self-stigma:** Stigma that the persons with dementia themselves experienced as a result of feelings of fear, shame, or apprehension towards behaviour that was associated with the disease.
- **Social stigma:** Misinformed social perceptions and beliefs of dementia that are inaccurate and detrimental to the public portrayal of the disease and those affected.
- **Structural Stigma:** Societal norms or institutional practices that were detrimental to the public perception of the disease and those affected.

### Discussions of Caregiver Distress and Difficulty in Accessing Healthcare

Here we identified any mention of *caregiver distress* with care, that is, distress that was brought about from caring for persons with dementia. Additionally, we identified any mention in the literature of persons with FTD experiencing *difficulties in accessing healthcare*.

### Discussions of Capacity or Autonomy

This code sought to identify reports of persons with dementia suffering a loss of autonomy in their daily lives. To identify this, we coded any instances of a *loss of occupation* or a *loss of driving license*. We also coded for any mentions of a lapse in *intellectual faculties*, which were usually depicted as changes in emotional processing or a lack of empathy.

### Use of Metaphors

This code identified any metaphors that were used to characterize or describe FTD. Our study coded for the following types of metaphors:

- **Personhood:** These were metaphors that either observed a radical shift in the personality of individuals with FTD or used an analogy to the onset of the disease as an entirely different mental state or, in many cases, a loss of personhood altogether.
- **Moralizing:** These phrases reflected language used to describe the disease in value laden terms.

## 2. Criminal and Socially Inappropriate Behaviour

### Criminal Behaviour Associated with the Disease

For this code we identify any reported criminal behaviour associated with the disease, according to the following sub-codes:

- **Theft:** Reports of theft that were related to acts of shoplifting or robbery.
- **Violence:** Reports of violent behaviour committed by persons with dementia, such as physically attacking roommates in care facilities, caregivers, or loved ones.
- **Sexual Crimes:** Reports of sexual crimes associated with FTD ranging from uncharacteristic sexual assault to persons with dementia possessing child pornography.
- **Trespassing:** Reports of persons with dementia trespassing on private property.
- **Traffic Violations:** Reports of persons with dementia committing traffic violations or being involved in motor vehicle accidents.

### Socially Inappropriate Behaviour Associated with the Disease

Frontotemporal dementia can also be associated with frequent socially inappropriate behaviour in persons with the disease that usually is not serious enough to bring legal charges yet is still alarming. Here we sought to identify the following:

- **Mismanagement of Personal Finances:** Reports of persons committing uncharacteristic or extravagant purchases.
- **Sexually Inappropriate Behaviour:** Reports of persons with dementia using adult pornographic material or making inappropriate sexual advances.
- **Social Misconduct:** Reports of any behaviour that was awkward, inappropriate for the situation, or off-putting, including disinhibited or profane speech and approaching strangers.
- **Public Indecency:** Reports of persons with dementia occupying a public space with indecent gestures or while being nude.
- **Public Urination:** Reports of persons with dementia urinating in a public setting.

### 3. Effect of Fitness to Stand Trial or Legal Responsibility

Our study sought to survey the extent to which the academic literature has addressed the moral gray area of persons with FTD in the legal realm. This domain endeavoured to capture any ethical or legal discussions surrounding the fitness or capability of persons with dementia to stand trial, as well as the different types of evidence that are admissible and how a person’s fitness to stand trial in the context of a dementia diagnosis is ascertained.

#### Effect of Fitness to Stand Trial

This code identified any mentions of persons with dementia being granted special considerations or deemed incapable of being held legally responsible for their actions due to their diagnosis. Sub-codes included:

- **Inability to Appreciate Morality/Legal Insanity Defense:** Any mentions of a legal entity recognizing a person with FTD as being incapable of appreciating the morality of their criminal actions, or a person with FTD using an insanity defense.
- **Mental Competence/Decision-Making Defect:** Any instance of a healthcare professional testifying that the person with FTD may have compromised decision-making or mental competence.
- **M’Naghten Test:** Any discussions regarding the M’Naghten, or the legal test for insanity in the US legal system.

#### Different Types of Dementia Evidence

Here, we coded the different types of evidence used in a legal defense or otherwise used to arrive at a diagnosis of frontotemporal dementia.

- **Neuroimaging:** Any mentions of neuroimaging technology used to indicate signs of frontal lobe atrophy in patients. The majority of literature in our sample referenced MRI, PET and/or SPECT scans.
- **Genetic Testing:** Use of genetic testing to determine a propensity to inherit FTD. Also included was literature that discussed counselling for those with a genetic predisposition for the disease.
- **Psychiatric Testing:** The use of expert witnesses or psychiatric scales/measures to verify a diagnosis of FTD.

## RESULTS

We encountered a variety of different themes, topics and issues discussed that need to be represented qualitatively and quantitatively in order to fully capture and represent the richness of the data. Presented below are several different excerpts from each code that better represent the diversity of topics encountered.

Table 2: Codes, Quotes, and Sources

Code	Excerpt
Criminal Behaviour Associated with FTD	She enjoyed visiting this private property daily despite being told that she would be prosecuted if she continued to visit. Also, she enjoyed emptying bags of trash from a moving car on the open road and watching each piece bounce on the ground (2).
Socially Inappropriate Behaviour Associated with FTD	As examples, one of our patients began placing her head into the car window of strangers to strike up a conversation, another began making open remarks in public about strangers’ obesity, and yet another lost his job after commenting inappropriately on the breast size of women working with him (24).
Stigma	Family members often experience guilt and shame because of the behaviour of the patient when taken care of at home, and various behavioural problems cause great challenges to family caregivers and to staff after admission to different types of institutionalized care (25).
Metaphors	Spouses commonly complained that the patient seemed foreign or ‘alien’, with a remote, blunted affect (24).  Had to distinguish between the demented patient and “the person he/she used to be,” as though they were two different people (26).
Legal Responsibility	Under the current legal system, in many jurisdictions, individuals affected by bvFTD who still exhibit preserved cognitive function might be considered to bear full moral and legal responsibility in the absence of strong evidence of neurocognitive dysfunction (5).
Types of Evidence: Neuroimaging	Neuroimages of individuals with bvFTD may show neural abnormalities, but those images alone cannot be used to diagnose the disorder. Neuroimages of individuals with bvFTD also often show distinctive types and variable degrees of atrophy to affected brain regions that differ from individual to individual. Thus, it is likely possible that a judge, due to the range of variability in neuroimages of bvFTD individuals and the fact that the neuroimages alone cannot be used to diagnose the disorder, could rule this evidence inadmissible in court (19).
Types of Evidence: Behavioural	Deficits in processing reward and punishment relating to future outcomes have been found in bvFTD patients using the Iowa Gambling Task (27).
Types of Evidence: Neurological	Evaluation for neurologic disorders and possibly neuropsychological testing, coupled with neuroimaging, is helpful in ruling out a neurodegenerative disease (18).
Capacity or Autonomy	In the vast majority of patients, the course of bvFTD is characterized by a progressive disability. Patients lose the ability of self-care, most patients become unable to carry out even the basal activities of daily living and ultimately become dependent on long-term care (28).
Recommendations	Specifically, when older adults start displaying behaviours that are criminal and a change from their baseline behaviour, an evaluation for neurologic disorders and possibly neuropsychological testing, coupled with neuroimaging, is helpful in ruling out a neurodegenerative disease. If identified, these individuals can then be appropriately channeled to available social resources (18).

## Pathology and Quality of Life

We found that the prominence of the FTD classification is higher when compared to the more specific bvFTD diagnosis. Although FTD (n=18) was the more prevalent characterization, bvFTD (n=15) was still a considerably common characterization of the disease. This result might suggest a growing acknowledgement of the specialization of the disease but could also denote the fact that ethical and legal issues are more frequently encountered in bvFTD (as opposed to, say semantic variant FTD). Many definitions included Frontotemporal Lobar Degeneration as simply ‘FTD’.

## Criminal and Socially Inappropriate Behaviour

The most common criminal incidences are theft, traffic violations and violence (see Table 3), which may suggest a predisposition of people living with bvFTD towards such behaviour. However, it should be noted that the severity of these crimes might increase the likelihood of such crimes being reported. As such, less egregious crimes such as trespassing, and public urination might be underreported and not as frequently observed in the literature or the media, and so different behaviours may have been under-reported (23).

**Table 3: Criminal Behaviour in bvFTD**

Criminal Behaviour	
Theft (13)	Violence (10)
Sexual Misconduct (4)	Public Indecency (2)
Public Urination (3)	Trespassing (6)
Traffic Violations (9)	

At the same time, socially inappropriate behaviour was less prominently discussed than criminal behaviour. Social misconduct (e.g., rude behaviour) is the most commonly discussed, followed by sexually inappropriate behaviour (e.g., lewd comments). Even though mismanagement of personal finances is mentioned, this issue has not received much attention.

**Table 4: Socially Inappropriate Behaviour in bvFTD**

Socially Inappropriate Behaviour	
Mismanagement of Personal Finances (2)	Sexually Inappropriate Behaviour (7)
Social Misconduct (9)	

## Stigma

In our sample, we found only three reported accounts of stigma suffered as a result of possessing FTD or an FTD diagnosis: each subcode reported only a single incidence of stigma. These results are promising in comparison to the larger incidence of stigma that was observed in a recent review of print media coverage of FTD. In fact, Nair & Dubljević (23) reported twenty incidences of social stigma, seven for self-stigma, and two for structural stigma. A smaller incidence of reported stigma in the literature might suggest a more balanced, non-stigmatizing portrayal in the scientific literature, including portrayals of the experience of living with dementia, as well as the social and structural stigma suffered as a result.

One such notable perspective offered with regard to mitigating stigma surrounding FTD was made by Trachtenberg & Trojanowski (29). They choose to draw attention to the stigma associated with the term ‘dementia’, especially in contributing to stigmatic perceptions, and describing the term as “A generalization that is pejorative and harmful based on historical and current patient, caregiver, and physician perspectives.” According to their recommendations, ‘dementia’ in the abbreviation FTD should be changed to ‘disease’ in order to “speak about frontotemporal disease to our patients and their families without stigmatizing this disorder or those facing the daunting challenge of living with it.”

Conversely, an FTD diagnosis might also elicit pro-social reactions, such as sympathy or pity for the person with the disease (19). This might provide benefit in criminal sentencing scenarios, so long as such reactions are informed by knowledge of the potential to regulate and monitor FTD tendencies. However, the sparse mention of self-stigma may be related to the lack of insight that is relevant to bvFTD; more empirical research needs to be conducted to confirm this association.

## Discussions of Burdens in Healthcare Access and Caregiver Distress

Our study observed 4 instances of discussions in the literature regarding burdens faced either by persons with FTD or their caregivers in accessing healthcare. Some articles cite the substantial burden that FTD patients present to both society and their caregivers, describing persons with FTD as causing “substantial financial loss and caregiver distress.” (19)

We also found five reports of caregivers mentioning distress regarding caring for someone with FTD or coping with life after FTD. Diehl-Schmid and colleagues (28) report that “patients with bvFTD are less likely to be cared for at home until death than patients with Late Onset Dementia (LOD). BvFTD caregivers are often faced with the double burden of providing care while



performing other roles, such as parenting, working, and managing the household.” Although there is a discussion regarding these issues in the literature, these topics merit further focus. In contrast to the four instances of discussion of this code, the study reporting on the print media sample encountered forty-three instances of discussions of both financial burdens and access to healthcare (23).

The need to focus more attention on accessible healthcare and guidance for persons with FTD and caregivers is compounded by the disparity in the availability of information regarding the nature of FTD and additional information in coping with FTD as well as counselling and support for caregivers. According to Sagbakken and colleagues (25), “caregivers of patients with FTD were significantly less satisfied with the provision of information about the disease, counseling, and follow-up concerning how to manage the situation compared with caregivers of patients with early-onset Alzheimer’s disease”. Finally, they point to findings “that caregivers, in general, need extensive support in coping with the situation of their family member with FTD.”

### Metaphors

Our study found a comparatively limited usage of both personhood (n=5) related and moralizing (n=3) metaphors. These results suggest a balanced, less stigmatizing portrayal of the experience of FTD and its depiction in the literature. In contrast, our public media sample found a much larger (n=63) incidence of both types of metaphors. This discrepancy suggests a need for better public communication regarding the onset, and changes in behaviour that are observed alongside FTD progression.

### Legal Responsibility

The legal dimension of FTD was of prime importance in our review, particular with regard to how the literature reported on the autonomy and agency of those with FTD. We found three instances of a legal insanity defense being used in criminal cases pertaining to FTD. In the context of the American legal system, one of the most common standards for determining legal insanity in half of US states is the M’Naghten test. Unfortunately, the criteria for legal insanity, that a person is “unable to appreciate the nature and quality of the wrongfulness of his acts” (30), do not accommodate the circumstances commonly found in cases of FTD, notably, that the person with FTD can, to an extent, appreciate the immorality of their action. By contrast, the Lund-Manchester criteria for legal insanity seem more applicable to circumstances in FTD, as highlighted by Diehl Schmidt and colleagues (2). The authors draw attention to the “German legal concept of ‘incapability of acting in accordance with the appreciation of the unlawfulness of an offense’” as a much more fitting test in the context of persons with FTD.

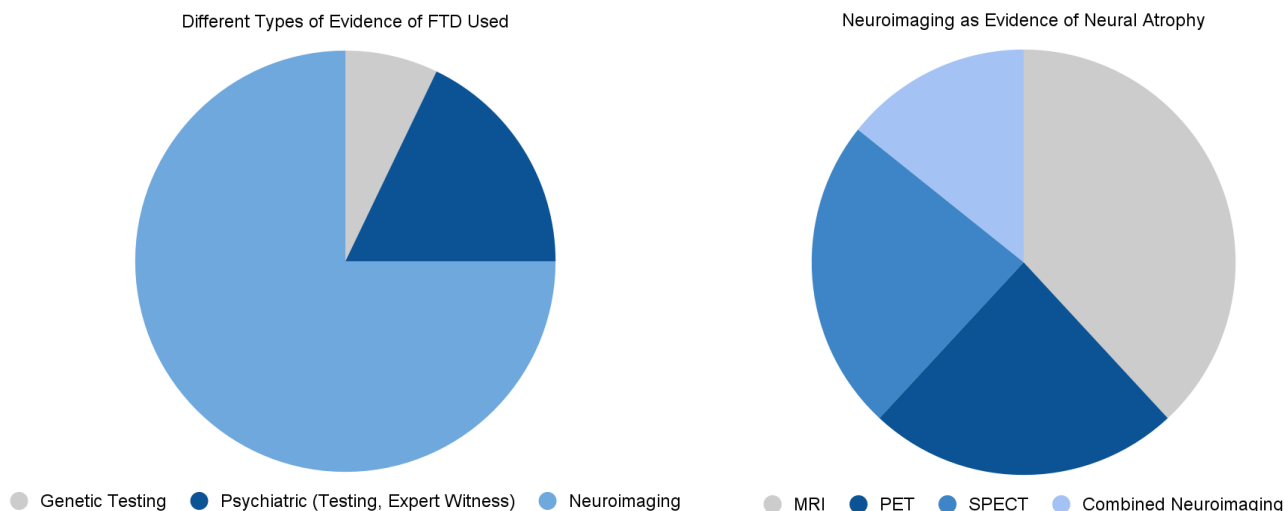
It is also important to highlight the many dimensions of cognition and mental ability that deteriorate or, in some cases, are lost entirely in FTD. Our study recorded mentions of lapses in memory, driving, and speech. As such, a new standard for mental disability in legal contexts should be developed, to incorporate these facets into determination of mental faculty and responsibility.

### Effect of Fitness to Stand Trial

The most common incidences of mentions of specific effects of fitness to stand trial are *Inability to Appreciate Morality/Unfit by Reason of Insanity* (n=4), followed by *Establishing Appropriate Legal Test* (n=3) and *Mental Competence/Decision-Making Defect* (n=2), which may suggest that these issues are not common. However, it should be noted that this may have been under-reported, and that future studies should access court records in order to ascertain actual prevalence.

### Types of Evidence

Figure 2: Evidence for verification of FTD



The neuroimaging code in our study returned some of our highest results. A prominent theme in the literature is the need for accurate and efficient methods of diagnosis that involve neuroimaging techniques. Baird, Kennett & Schier (21) mention that the characteristic “frontal executive dysfunction, identified by cognitive assessment or frontal lobe pathology on neuroimaging investigations, was common and reported in 10/30 cases.” We found that MRI was the most mentioned neuroimaging method used to corroborate FTD (n=8). However, other methods were also prevalent, as shown in Figure 2. Our sample also suggests that the most effective method is a combination neuroimaging techniques. Since there is no clear physiological marker for FTD, neuroimaging becomes even more important as a method for detection (31).

It is important, however, to recognize that neuroimaging is not the only method to rely in either detection of FTD, or the submission of evidence that confirms an FTD diagnosis. Berryessa (19) states,

Although neuroimages of individuals with FTD can be used to demonstrate neural abnormalities or the presence of FTD, these abnormalities can vary widely from person to person. As a result of this variability, a judge may rule this evidence inadmissible. These pieces of evidence might also work against the person in question, suggesting to a judge or jury that specific brain regions associated with moral faculties have deteriorated and as a result, the consequential immoral behaviours that may have led them to criminal circumstances are out of their control.

The observed variability in brain scan evidence can also prove difficult in the case of expert testimonies. Baird, Kennett & Schier (21) highlight several cases where expert witnesses reported conflicting interpretations of MRI brain scans of FTD, describing them as “inconsistent with a diagnosis of FTD.”

Despite neuroimaging being the most common form of admitted dementia evidence (n=21), psychiatric measures, which include psychiatric tests or expert witnesses, were reported in our sample in five separate instances. In fact, Baird, Kennett & Schier (21) also report that in their investigations, 58% of expert witnesses were psychiatrists, and 21% were psychologists.

## Capacity or Autonomy

Discussions of capacity and/or autonomy and their subsequent loss due to FTD were much less prevalent as compared with the study of the print media sample (4). There seems to be a shift in focus towards intellectual deficits (n=6) rather than the effects of FTD on social markers of capacity such as driving (n=1) and occupation (n=2).

## Recommendations

We encountered several different recommendations for dealing with FTD. Although some of these recommendations were intended for persons with FTD (n=2), the vast majority were directed toward caregivers (n=9) or healthcare providers (n=6).

When previously law-abiding middle aged or older patients suddenly start committing minor crimes, particularly theft or shoplifting, a neurodegenerative brain disorder should be considered, and a thorough psychiatric and neurologic examination arranged. If the patient has a diagnosis of FTLT, the patient's family needs to be informed that the crimes are a symptom of the disease rather than the patient's fault (2).

Other recommendations suggest effective strategies for fostering trusting and informed relationships between caregivers and their healthcare providers.

Non-pharmacological interventions should be also directed to the patient's caregiver, in order to help them to develop strategies for managing behavioral disturbance, modifying the living environment and reducing burnout. We think that there is the need of a multidisciplinary team with specific disciplines, such as neurologists, psychiatrists, neuropsychologists, social worker, occupational therapist, neurorehabilitation professionals, and nurses, that can identify a multimodal rehabilitation program for the patient and an educational program for caregivers (32).

## Additional Issues

Several emergent issues that could not be accurately captured as *themes* (since they were single instances) still merit being mentioned. These include: 1) the effect of Tau pathology on incidence of crime (18); 2) brain donation for FTD patients (33); 3) the fact that police officers are increasingly becoming first responders for elderly FTD patients (34); and 4) the need for reconsidering the punishment of individuals with dementia (19).

## DISCUSSION

**Specific ethical issues:** There seems to be a growing acknowledgment of bvFTD as deserving separate attention from broader FTD, notably with a shift in focus toward intellectual deficits, rather than the effects of FTD on social markers of capacity, such as the ability to drive or continue working. That said, this does not translate into a fine-grain analysis of specific issues pertaining to the disease. For instance, with intellectual deficits (n=6), the present results are much less specific than

the results of the print media analysis, which noted higher instances of “loss of speech” (n=28) and “loss of memory” (n=24) reported by the media (23). This may be due to the fact that the academic audience is already better informed about specific deficits, unlike the general public, which needs to be provided with adequate background in order to grasp the ethical issues.

Portrayal of stigma in the academic literature (n=3) seems significantly reduced in comparison to the public media representation of FTD (n=29). A smaller incidence of reported stigma suggests a balanced and non-stigmatizing portrayal in the scientific literature of the experience of living with dementia (23). Similar to the observed disparity between academic and public media samples, this diminishment might be a result of a more informed discussion in the academic literature as opposed to public media environments, especially regarding the social and structural elements surrounding FTD.

The fact that FTD patients consider themselves to be fully autonomous – whereas their family members need to manage their behaviour to avoid financial, reputational, and even criminal-justice repercussions – can cause significant strain and caregiver distress. Furthermore, most dementia care is geared toward Alzheimer’s, which decreases the legitimate options and resources these family caregivers have at their disposal, and that is arguably unfair. Although there is some discussion regarding the burden FTD patients may place on caregivers and society, the low incidence of these discussions (n=4) in contrast with the weight of their potential answers highlights that more focus should be placed on these topics. Solutions to these dilemmas can potentially provide the most effective methods of improvements in the quality of life of not only persons with FTD, but their caregivers as well. Although there are recommendations for caregivers in dealing with the stress and burden of caring for a loved one with FTD, these recommendations vary widely and may not be universally applicable. Thus, more concrete and consistent suggestions are needed for the healthcare or academic communities.

**Specific Legal Issues:** Results here show broad recognition of the relationships between bvFTD and particular types of criminal behaviour, particularly theft, traffic violations, types of reactive violence, and sexual crimes. As crimes associated with bvFTD are thought to be influenced by the disinhibition, punishment insensitivity, and lack of empathy associated with the disease (18,19), it is unsurprising that offenses widely discussed in existing literature appear to stem from impairments to moral decision-making and impulse control (4,19). However, it should be noted that some of these crimes, especially theft, violence, and sexual crimes, may be more likely to be reported than quality-of-life crimes, such as public indecency; thus, some criminal or property offenses may be under-reported or less likely to lead to criminal justice system involvement (23).

Our review also suggests existing interest and concern about the involvement of individuals with bvFTD. Although bvFTD has been thought to raise a range of complex legal issues (17,19,21,35), results indicate that to date this literature’s primary focus has been on how evidence of bvFTD is used in trial proceedings, and, to a lesser extent, issues related to determining and standards of legal insanity in cases involving bvFTD (i.e., the M’Naghten Rule). A range of different types of evidence on bvFTD, including neuroimaging data, psychiatric or neuropsychological reports, and genetic testing, have been discussed to support diagnoses of bvFTD in legal proceedings (19). Yet, neuroimaging data appears to be by far the most prevalent way of supporting diagnoses of bvFTD in legal proceedings, with a combination of MRI, SPECT, and PET methods used to accurately and efficiently provide evidence of a diagnosis, with oftentimes little reference to other diagnostic criteria (21,35).

This is surprising, given that neuroimages alone cannot be used to diagnose the disorder, with both short- and longer-term clinical tracking and third-party corroboration of behavioural changes considered imperative to an accurate diagnosis (17). Indeed, there is no clear neurological or physiological marker for FTD, with neuroimages of individuals with bvFTD often showing distinctive types and variable degrees of atrophy to affected brain regions that can differ from individual to individual (19). Unsurprisingly, the fact that evidence of and areas of atrophy can range for those with bvFTD likely contributes to why expert opinion in legal proceedings can often conflict on whether neuroimaging findings in particular cases ‘prove’ or show a defendant’s bvFTD diagnosis (32).

Given the prevalence and role that neuroimaging evidence appears to hold in legal proceedings as tests or proof of bvFTD, those involved in the legal process, who are unlikely to be familiar with its complex methodology, should be more educated about neuroimaging in general, as well how neuroimaging evidence on bvFTD should be used to support a bvFTD diagnosis. Particularly, as neuroimaging only represents one of three criteria needed for diagnosis (17), legal decision-makers, including defense attorneys, prosecutors, and judges, should be aware of the limitations of and potential errors in using neuroimages as the sole or chief proof of bvFTD without other clinical and behavioural evidence.

Further, although broadly noting how neuroimaging evidence can be used to substantiate a bvFTD diagnosis, existing literature still appears quite limited in examining how such evidence can also be used to show how the disease’s symptomatology affected an individual’s decision-making, potentially contributed to offending, and if and how such evidence may influence legal decision-making at different legal stages. Broader literature on the use of neuroimaging evidence at different legal stages in criminal trials shows that it is most often presented when and may be most relevant to 1) determining a defendant’s competency, and 2) determining a defendant’s punishment at the sentencing stage (36). However, discussions on the use of such evidence during these two legal stages in cases involving bvFTD appeared in only a small fraction of the literature included in this review. Particularly, Berryessa was one of the few authors to discuss how neuroimaging evidence may lead to questions on the potential moral blameworthiness of offenders with bvFTD, as well as the court’s potential hesitance regarding the use and utility of deterrent or retributive punishments for such defendants (19). This suggests the need for a broader examination of the use and potential influence of neuroimaging evidence on bvFTD during these other legal stages, particularly punishment.

Moreover, bvFTD is diagnosed by formal clinical criteria that are accepted as the standard, at least in the US. Many different conditions can be mistaken for bvFTD, especially psychiatric disorders; hence, focusing on neuroimaging or other measures, or relying on cases where patients were diagnosed by clinicians with insufficient expertise (as opposed to trained neurologists) may further complicate the issue.

Finally, to date, the literature has focused almost exclusively on the legal relevance of bvFTD in court settings; however, emerging issues noted in this review suggest that a wider examination and discussion of how bvFTD may intersect with the legal process is warranted. Particularly, police officers are those most likely to be first responders to events involving patients with FTD that are exhibiting criminal behaviour (34). Future studies should thus consider police officers' knowledge of bvFTD, how the impairments associated with the disease may cause complications in interactions between individuals with bvFTD and law enforcement, and whether and what types of training for these situations is needed.

## CONCLUSION

Our study began as an attempt to expand upon work from our prior print media literature review that cataloged the experiences of both persons with FTD as well as their caregivers. In this regard, it is reassuring to note that the academic discussion of bvFTD seems more balanced than the print media, with an increased emphasis on criminal behaviours rather than socially inappropriate acts and language that characterize the disease in ways that are less stigmatizing. Nonetheless, the present review revealed several emerging themes that require further attention from the scientific community. To begin with, the relatively little discussion on matters of caregiver distress and burden is concerning, since, according to our print media sample, caregivers tend to feel overlooked and overburdened following a bvFTD diagnosis. Although strategies for coping with the burden of caring for a person with bvFTD and managing the disease are beginning to emerge in public discussion, these topics need equal if not greater attention from the academic community, as researchers and clinicians are better equipped than journalists to comment on coping strategies and techniques for disease management, as well as providing further resources. Finally, this paper highlights some of the specific legal issues that still merit attention from jurisprudence experts. One such matter is the range of legal criteria that could be used to classify legal insanity for a person with FTD. The criteria that determine this classification are of utmost importance, as they have tremendous bearing on the fates and legal responsibilities of bvFTD offenders and often determine whether they receive help, medical intervention, or legal punishment. The apparent obsolescence, at least for bvFTD, of one of the most common current legal tests for insanity in the US (the M'Naghten Test), as well as the existence of more contemporary legal insanity tests in countries such as Germany (the Lund-Manchester criteria), reaffirms the importance of implementing more robust legal insanity criteria to effectively approach the complicated disease of bvFTD and its consequential changes in behaviour. Future work should also consider the relevance and impact of bvFTD for other commonly used tests of legal insanity in the US, such as the standard under the American Law Institute Model Penal Code, which has not been sufficiently discussed in the literature. Finally, another similar issue of legal importance is the role of expert witnesses in cases involving bvFTD and the different types of evidence plaintiffs and defendants may be allowed to submit for testimony in court. Thus, more careful academic discussion on these legal issues, as informed by knowledge of the medical nature of bvFTD, will help to mitigate the demonization and misunderstandings of persons with bvFTD and their related offending.

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None to declare

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