



The Principle of Autonomy and Behavioural Variant Frontotemporal Dementia

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Abstract Behavioural variant frontotemporal dementia (bvFTD) is characterized by an absence of obvious cognitive impairment and presence of symptoms such as disinhibition, social inappropriateness, personality changes, hyper-sexuality, and hyper-orality. Affected individuals do not feel concerned enough about their actions to be deterred from violating social norms, and their antisocial behaviours are most likely caused by the neurodegenerative processes in the frontal and anterior temporal lobes. BvFTD patients present a challenge for the traditional notion of autonomy and the medical and criminal justice systems. Antisocial behaviour is often the earliest recognized manifestation of bvFTD. Given that the symptoms are not specific and that atrophy of the frontal lobes is only observable with structural neuroimaging in the later stages of the disease, it is hard to ascertain their autonomy. Recently proposed reconceptualizations of autonomy (Dworkin's, Jaworska's, and Dubljević's) can, however, be sufficiently redefined to provide explicit rules and offer nuanced guidance in such cases. A combination of notions of autonomy gives the most nuanced guidance with three modifications: 1) including socio-moral judgement in the notion of "normal cognitive competence," 2) excluding in-principle unendorsable ideals from the notion of "capacity to value," and 3) redefining ideal-typical degrees of compulsion (mild, severe, and total).

Keywords Autonomy · Behavioural variant frontotemporal dementia · Moral responsibility · Legal issues · Informed consent

Introduction

Autonomy is without doubt one of the most important principles in bioethics and perhaps the key prerequisite for ascribing moral and legal responsibility in Western democratic societies. It is also an important social phenomenon, underlying interpersonal relationships (most notably for taking responsibility for others), social standing, and reputation. In bioethics, principles such as autonomy have served the purpose of defining and protecting patients' rights against encroachment from unwanted biomedical interventions and outside actors. However, the progress in biomedical, social, and behavioural sciences has also influenced the way autonomy is conceptualized in terms of accommodating findings that seem to undermine traditional notions of autonomy (Racine and Dubljević 2017). Such recent reconceptualizations include Dworkin's views on "critical interests" in late-stage dementia (Dworkin 1993), Jaworska's critique and alternative conception (Jaworska 1999, 2006), and Dubljević's post-metaphysical notion of autonomy (Dubljević 2013, 2015, 2016). In this paper, I use the method of wide reflective equilibrium (Rawls 1971), a prominent method of justification in ethics (Daniels 2018), to test the normative and empirical usefulness of these reconceptualizations of autonomy. This implies a

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coherence procedure of applying general principles from theories of autonomy to specific moral intuitions relating to behavioural variant frontotemporal dementia (bvFTD). The case of bvFTD poses very specific challenges for the notions of autonomy and responsibility, which need to be thoroughly analysed and general principles from theories and moral intuitions need to be weighed until they are consistent and coherent.

I start by describing the condition of bvFTD and the ways in which it presents a challenge to traditional concepts of autonomy. Then, I briefly introduce the three re-conceptualizations of autonomy. Finally, I analyse the lessons learned from the application of autonomy to the case of bvFTD for the criminal justice and medical system as well as for the general social “life-world.” I argue that the marked deficits in autonomy justify diversion of individuals living with bvFTD from regular courts into specialized “problem-solving courts” for dementia, similar to drug and mental health courts. Then, I advocate for contextualizing the assent procedure in the medical system. Last but not least, I argue for the need to de-stigmatize the condition in order to decrease unjustified social isolation and to encourage treatment-seeking.

The Unfortunate Condition With “No Concerns”

In bvFTD cases, which are the most common type of frontotemporal dementia (Chare et al. 2014), individuals may commit immoral and illegal acts that have lasting repercussions for them and their families (Mendez, Anderson, and Shapira 2005). BvFTD is characterized by an absence of obvious cognitive impairment (Lanata and Miller 2016) and presence of symptoms such as disinhibition, social inappropriateness, personality changes, hyper-sexuality, and hyper-orality (Rascovsky et al. 2011), in addition to markedly impaired socio-moral judgements (Manes et al. 2011). The disease progression invariably starts with disinhibition and leads to focal atrophy of the frontal and temporal lobes or “frontotemporal lobar degeneration,” which has historically been named “Pick’s disease” (Birkhoff, Garberi, and Re 2016). Ultimately, bvFTD ends in death, in most cases approximately five years after the diagnosis has been made (Chare et al. 2014). However, in the early stages of the disease’s progression, only the family and close friends of the afflicted individual are aware that there might be a problem. The affected

person starts making decisions and taking actions that are increasingly disinhibited and socially inappropriate while at the same time manifesting a lack of concern. This lack of concern is evident in behaviours and responses regarding social approbation (e.g., no concern whatsoever for fondling private parts in front of others) and financial well-being of self and family (e.g., no concerns regarding indiscriminate sharing of sensitive or personal information such as credit card or social security number) (Rascovsky et al. 2011).

Besides embarrassing or imprudent actions, individuals living with bvFTD often engage in antisocial behaviours: reported cases include unsolicited sexual behaviours, traffic violations, physical assaults, theft, breaking and entering, paraphilia, and compulsive gambling (Birkhoff, Garberi, and Re 2016). Antisocial behaviour is often the earliest recognized manifestation of bvFTD. Given that the symptoms are not specific, intellectual functions are preserved, and atrophy of the frontal lobes is only observable with structural neuroimaging in the later stages of the disease, it is hard to know whether the individual is autonomously violating socio-moral norms or whether their autonomy is diminished. In fact, the disease is usually diagnosed three to four years after the onset (Chare et al. 2014), which is plenty of time for the affected individual to inflict serious financial and reputational damage.

There are no FDA approved treatments for bvFTD and no pharmacological agents treating the root cause appear to be forthcoming (Birkhoff, Garberi, and Re 2016). In bvFTD, a fundamental issue is that the individual appears to be afflicted by a specific disorder of socio-moral decision-making, as evidenced by repeated decisions and actions that are against the person’s best interest and failure to learn from repeated mistakes in spite of having more or less intact intellect, memory, and other cognitive functions (Manes et al. 2011). Also, research on moral judgement has demonstrated that bvFTD patients are more “utilitarian” than healthy controls or Alzheimer’s Disease patients (Mendez, Anderson, and Shapira 2005) and that they exhibit impaired integration of intentions and outcomes (Baez et al. 2014). Whatever the underlying cognitive differences between bvFTD cases and others may be, the specific prefrontal dysfunction seems to result in criminal behaviour in more than half of the cases (Lanata and Miller 2016), while some even speculate that the numbers may be higher (Diehl-Schmid et al. 2013) and

that bvFTD patients have a “unique predisposition to criminal violations” (Mendez 2010, 318).

The practical implications are considerable: 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 (Manes et al. 2011).¹ Decisions made by persons in the early stages of bvFTD are considered fully autonomous by default, and this creates a tremendous burden for the families that find themselves impoverished due to impulsive financial decisions or torn because one of their members starts acting out and stealing or sexually harassing other people. Even in cases where clinical diagnoses of bvFTD have been made, patients are labelled as “possible bvFTD” most of the time. The consensus guidelines from experts in the medical community require that three types of characteristic symptoms are persistent or recurrent in order for “possible” bvFTD diagnosis to be delivered (Rascovsky et al. 2011). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), as well as the expert guidelines, recognize the additional diagnosis of “probable” bvFTD: in these cases, the patient meets criteria for “possible bvFTD,” exhibits functional decline, and has frontal hypometabolism or atrophy revealed by neuroimaging (Lanata and Miller 2016). According to expert guidelines, diagnosis of “definitive” bvFTD requires histopathological evidence on biopsy or at post-mortem (Rascovsky et al. 2011). However, the DSM-5 does not include the “definitive bvFTD” diagnostic category (Lanata and Miller 2016). Therefore, even though pre-mortem diagnosis is theoretically attainable, the status of affected individuals in the early stages of the disease progression as autonomous members of society is likely to remain the same under the default concept of autonomy used for ascribing moral and legal responsibility.

The discussion regarding the core concept of autonomy in individuals in the early stages of bvFTD is yet to happen, whereas the related discussions on derivative concepts, such as legal capacity and moral culpability, has started only recently (Mendez 2010; Manes et al.

2011; Birkhoff, Garberi, and Re 2016). This is especially relevant for the subset of patients that have the slow-progression variant, also known as bvFTD phenocopy syndrome, which have typical behavioural signs lasting up to twenty years and do not show clear biomarker evidence of frontal atrophy (Lanata and Miller 2016). To date, however, there are no answers—only the questions remain. How should a bvFTD patient’s diminished autonomy factor into our social, legal, and moral assessment of their actions? Should society simply deprive individuals suspected of succumbing to the disease of their legal right to dispose of their property, and should it even declare that bvFTD patients are not culpable for stealing or sexual harassment? Or should the legal system take its course as usual, by punishing these individuals and allowing them to make bad financial decisions and gamble away the resources needed for their families to take care of them in the later stages of the disease’s progression?

The answer hinges on the concept of autonomy being used as a benchmark for informing the legal system. Erring on the side of autonomy is usually in the best interest of patients, but doing so is arguably harmful in bvFTD cases. The traditional philosophical concept of autonomy (Frankfurt 1971), when connected to the legal construct of “cognitive capacity” (Dworkin 1993), leads to a “business as usual” and “tough luck” attitude. Numerous studies have concluded that patients with bvFTD understand social rules and conventions, as well as the consequences of their behaviour (Diehl-Schmid et al. 2013), and this makes them clearly culpable under the M’Naughten legal rule (Birkhoff, Garberi, and Re 2016). Indeed, bvFTD patients do not “disown” their actions, nor do they lack the capacity to discern right from wrong. For instance, Mendez reports the case of a woman in her fifties who underwent progressive personality changes and started committing petty theft at retail establishments:

When her specific behaviours were pointed out to her, she could describe them in detail, and she endorsed knowing that they were wrong. When asked why she engaged in such behaviour, she would shrug and say, “That’s me.” (Mendez 2010, 319)

Arguably, our commonly held moral intuitions suggest that there should be a meaningful difference between competent adults and bvFTD-affected persons

¹ This “default” approach is shared by many jurisdictions in the West, most notably in countries with the common law tradition. As succinctly formulated by Hardcastle “Western law assumes that all adults are rational beings who act for specific reasons ... In other words, courts do not care about issues of impulse control, impaired executive functioning, and the like” (Hardcastle 2018, 325).

even in the early stages of the disease's progression. In fact, in some reported bvFTD cases from Europe, the continental legal system acknowledges the intuitive judgement of psychiatrists and neurologists, and persons affected by bvFTD are deemed not autonomous. In Italy, a case of a male bvFTD patient engaged in stealing was resolved by declaring him “mentally incapacitate” but not “socially dangerous” as long as he is “continuously monitored by his wife and doctors” (Birkhoff, Garberi, and Re 2016, 162). Similarly, in Germany, the law allows considerable leeway for judgement of psychiatrists by including the provision of being “incapable ... of appreciating the unlawfulness of their actions or *of acting in accordance with any such appreciation* due to ... serious mental abnormality,” which allows German experts to conclude that the “patient's family needs to be informed that the crimes are a symptom of the disease rather than the patient's fault” (Diehl-Schmid et al. 2013, 76, emphasis added). Even in the United States, where bvFTD patients with antisocial behaviour would not pass legal criteria for judgements of “not guilty by reason of insanity,” commonly held intuitions about autonomy, which seem to be in stark contrast with explicit rules and principles, play an important role in convincing plaintiffs, complainants, and prosecutors not to press or to drop charges. In the criminal cases with bvFTD patients in the United States, the majority are resolved through the dropping of charges either by plaintiffs or prosecutors; in other cases, individuals are prosecuted but not incarcerated; and in other cases still, patients “escape justice” by succumbing to the progressive nature of the disease, which ultimately leads to death (Mendez 2010).

Now, intuitive judgements about autonomy have been useful in this regard, but without amendment, current rules cannot prevent abuse. Note that considerable leeway exists for psychiatrists to strip healthy elderly individuals of their right to manage their own affairs based on minor traffic violations and risky investments. These intuitive judgements regarding lack of autonomy, which are evidently at play, may be based on feelings of sympathy, care, paternalism, and perhaps pity (Christman 2015). However, even though intuitions regarding the compromised autonomy in bvFTD patients play an important role in the moral and legal domain, principles of autonomy should be able to accommodate new scientific and clinical findings regarding tough cases and explicitly account for the bases of the commonly held intuitive judgements. The traditional

hierarchical concept of autonomy (Frankfurt 1971, 1988) seems to be unhelpful in such cases. Namely, according to this model, an action is autonomously chosen by an agent if his or her first-order desire to commit the act is sanctioned by a second-order volition endorsing the first-order desire (Frankfurt 1988; Dryden 2017). The origins of these desires are irrelevant on this view since the agent's identification is what is crucial for autonomy (Frankfurt 1988).² The apparent rationality, lack of external influences, and (more or less) authentic endorsement of immoral and even criminal behaviour makes bvFTD patients fully autonomous on this view of autonomy. However, more recent re-conceptualizations of autonomy might give different answers and be better able to accommodate our intuitions.

Neurology, Neuroscience, and Re-Conceptualizations of Autonomy

Recent re-conceptualizations of autonomy have been motivated by problematic cases stemming from neurology (U.S. Congress, Office of Technology Assessment 1987), progress in behavioural and brain sciences (Felsen and Reiner 2011), and public discussions about neuroscientific experiments that seem to put freedom of choice into question (Libet 1985; Racine et al. 2016). I analyse three such proposals and explore if they give a more nuanced guidance for the case of bvFTD. In what follows I employ the method of reflective equilibrium (Rawls 1971): an established coherence procedure for justification in logic, ethics, and political philosophy (Daniels 2018). By aligning moral intuitions with general principles from the three theories of autonomy, it provides better clarity on whether and how specific morally disputed practices are more likely to be correct or wrong. The method of reflective equilibrium is not unlike what is commonly practiced during moral

² An argument could possibly be made (by strong supporters) to salvage the usefulness of the Frankfortian concept of autonomy in bvFTD. However, that would take a strong supporter actually doing the work of re-conceptualizing, which may or may not be fruitful. Either way, there is a strong presumption that re-conceptualizations (some of which draw on Frankfurt) may be more appropriate in application (see discussion below). In fact, Dworkin's view may be seen as an extension of Frankfortian autonomy, informed by neurology and neuroscience and applied in the context of dementia. As such it avoids some of the unfortunate language that is traditionally used, while better aligning the principle of autonomy with relevant scientific findings and intuitions in the specific case of dementia.

deliberation: while reflecting on a course of action, a moral agent frequently considers fairly general reasons and principles, which may lack specificity. The agent then assumes that these may offer suitable guidance if they are not leading to implications they would not be able to accept in a different context, but oftentimes leads to revisions or specifications of the principles. Initial intuitive impressions are also revisable if they find no principled grounding (see Daniels 2018).

Now, using only one theory of autonomy would be merely ironing out inconsistencies in a singular set of beliefs (or a “narrow reflective equilibrium”). In order for the method to have a more general reach (or to become a true “wide reflective equilibrium”), it needs to be tested by several well developed positions. The hope is that by broadening the field of relevant moral beliefs as designated by neuroscientifically informed theories of autonomy, there will be evidence that the resulting principles constitute a reasonably stable conception of autonomy. Our beliefs about autonomy are justified if they cohere in such a wide reflective equilibrium and are applicable in a full range of specific cases in need of principled guidance. Thus, I now turn to the three theories of autonomy.

Dworkin’s View

Ronald Dworkin (Dworkin 1993) has offered a reconceptualization of autonomy for the cases of late-stage dementia. Even though he focuses on Alzheimer’s, this view is motivated with accommodating relevant clinical and neuroscientific findings into one of the most important moral and legal concepts. Dworkin differentiates between “critical interests,” such as those conforming with firm convictions and values, and “experiential interests,” such as doing things one immediately likes (Dworkin 1993). These are not unlike first- and second-order desires in the traditional, hierarchical conception of autonomy, and Dworkin uses them to explain the standard case of loss of autonomy in addiction: “mind changing drugs or other forms of brainwashing that produce long-lasting pleasure and contentment are not in their victim’s [...] *critical interests*” (Dworkin 1993, 202). According to Dworkin, people with dementia have both experiential and critical interests (as opposed to persons in coma or vegetative state, who only have critical interests). This may lead to a conflict, where

experiential interests lead to decisions that are against the critical interests of a person. This is not to say that fully autonomous persons do not make bad choices sometimes drawn by their experiential interests. As Dworkin notes, “[c]ompetent adults are free to make poor investments, provided others do not deceive or withhold information from them ... ” (Dworkin 1993, 222).

Dworkin’s criteria for loss of autonomy are very much focused on cognitive capacities and information processing. For instance, he argues that a “demented person” “has no right that his choices about a guardian (or the use of his property or his medical treatment, or whether he remains at home) be respected for reasons of autonomy” (Dworkin 1993, 225). That is because persons in the late stages of dementia,

have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self [...] fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation [...]. They cannot have projects or plans of the kind that leading a critical life requires. They therefore have no contemporary opinion about their own critical interests. (Dworkin 1993, 230)

This leads Dworkin to conclude that the prior choices of a *person* who has become demented (as stated in an advanced directive), has precedence over the choices of the currently *demented person*, who has critical interests but is unable to grasp them, and is ultimately driven by experiential interests. Dworkin’s case for late-stage dementia is clear, but what does this view entail in cases of early stage dementia?

Again, Dworkin stresses cognitive competence:

[w]hen a mildly demented person’s choices are reasonably stable, reasonably continuous with the general character of his prior life, and inconsistent and self-defeating only to the rough degree that the choices of fully competent people are, he can be seen as still in charge of his life, and he has the right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed, systematically or randomly contradict one another, reflecting no coherent sense of self and no discernible even short-term aims, then he has presumably lost the capacity that is the point of autonomy to protect. (Dworkin 1993, 225)

The crucial point in applying Dworkin's view to cases of bvFTD would be to consider whether they are able to grasp their "critical interests," to form "short-term aims," as well as to have a "coherent sense of self." Before trying to disentangle these issues, however, it is important to consider an important critique of Dworkin, specifically aimed at his views on early stages of dementia.

Jaworska's Critique and Alternative Reading of Autonomy in Dementia

Agnieszka Jaworska, in her critique of Dworkin (Jaworska 1999, 2006), de-emphasizes cognitive aspects of autonomy and focuses on the ability to value while making a distinction between desires and values. Desiring is a more basic, first-order notion, while valuing involves a type of second-order reflection. She also defines two features of valuing: "the person thinks he is correct in wanting what he wants, and achieving what he wants is tied up with his sense of self-worth" (Jaworska 2006, 286–287). Based on this contention, Jaworska argues that Alzheimer's patients in early stages of the disease progression are in fact autonomous. She notes that "... in the context of dementia ... , so long as [the person] still holds values, he is capable of self-governance and can form new critical interests" (Jaworska 1999, 134; see also Menzel and Steinbock 2013).

Jaworska gives the example of Mrs D, an Alzheimer's patient interviewed in a study: this person displayed pronounced memory deficits—in fact, she could not keep track of time or her own age—but could perform most fundamental acts of valuing that are crucial for autonomy. Mrs D often volunteered to be a research subject in order to help others, and according to Jaworska she had no need to review her whole life in order to affirm this conviction:

[w]hat mattered for her was that this felt right to her, then and there. One has the sense that Mrs D was simply enacting a basic part of her personality, one that had remained relatively intact despite her other impairments. (Jaworska 2006, 93).

Jaworska defends the view that the immediate interests of an individual, even in cases of dementia, shouldn't be overridden as long as this individual has the ability to value. As for the early cases of dementia, she claims that,

Alzheimer's patients usually retain their ability to value long after other capacities [...] are gone. For example, Mrs D's conviction that she ought to help her fellow man in any way she could certainly comes across [...] as a truly self-given authentic principle of conduct. (Jaworska 2006, 98)

The crucial point in applying Jaworska's view to cases of bvFTD would be to consider whether they retain their "capacity to value" and thus create new "critical interests." Again, before trying to disentangle these issues, it is important to consider another view that tries to define and clarify loss of autonomy in compulsive acts.

Dubljević's Post-Metaphysical Notion of Autonomy

Unlike traditional concepts of autonomy, which focus on cognitive capacities, such as deciding with sufficient information and understanding, Dubljević emphasizes additional important components of autonomous actions: the volitional component (presence of a competent decision-maker who acts voluntarily or intentionally) and the liberty component (deciding without external or internal controlling influences that would override already chosen actions). His post-metaphysical notion of autonomy centres on the idea that with the advent of democracy, autonomy, and rights are fundamentally based on democratic authority and empirically observable capacities, not metaphysical or religious doctrines (Dubljević 2013, 2016).

Dubljević defines autonomous action, to which responsibility can be ascribed, in the following way:

An agent acts autonomously when she/he: (a) endorses decisions and acts in accord with internal motivational states, (b) shows commitment to them in the absence of undue coercion and compulsion, and (c) could as a reasonable and rational person continue to do so after a period of informed critical reflection. (Dubljević 2013, 46)

Unlike many other notions of autonomy, in this view, controlling influences such as coercion (external) or compulsion (internal) do not automatically reduce autonomy but need to be assessed for their degree and justifiability. Dubljević identifies three ideal-typical degrees of coercion:

1. Indirect coercion—defined as influences through expected utility;
2. Direct coercion—characterized by sanctions for non-compliance; and
3. Total coercion—characterized by actual exertion of physical force or restraint. (Dubljević 2013, 47)

On this reading of autonomy, coercion might reduce autonomous action only if it is unjustifiable, and most justified instances of coercion are responses to unjustified attempts at coercion of equal or greater ideal-typical degree. For instance, a legal ban on robbery is a justified coercive response of society to unjustifiable coercive attempts of individuals. Thus, a person acting in accordance with the wishes of a pistol wielding robber is considered not autonomous in this particular instance because the act was done under threat, whereas acting in accordance with the law is considered autonomous in all cases, whether the decision was made due to the threat of legal sanctions or not. Even total coercion might be justified and committed in order to restore autonomy. For instance, a person might be legitimately physically restrained if they are severely intoxicated and violently aggressive towards others. They would not be considered autonomous, not because of the restraints (which are allowed precisely because a person is no longer autonomous) but due to lack of self-control caused by intoxication. Indirect coercion is expected to be resistible by adult individuals (as opposed to minors) and so it does not constitute a reduction of autonomy. The difference between unjustified and justified instances of coercion hinges on the public exercise of autonomy (e.g., laws in democratic societies) and presupposes the possibility that some external influences could be endorsed and incorporated in a long-term rational life-plan after a period of informed critical reflection—but not that this critical reflection actually took place for this specific individual (Dubljević 2013).

Similar to the notion of coercion, Dubljević differentiates between different ideal-typical degrees of internal influences, or compulsion:

1. Mild compulsion—defined in terms of reversible psychological dependence;
2. Severe compulsion—defined in terms of reversible physiological dependence; and

3. Total compulsion—defined as irreversible physiological dependence (Dubljević 2013, 48)

Once again, not every kind of compulsion reduces autonomy. Mild compulsion is something that competent adults (as opposed to minors) could in fact resist, but even if they do not on occasion, this does not mean that they are no longer autonomous. However, even irresistible compulsions do not necessarily reduce autonomy. Dubljević gives the example of the need to consume oxygenated air, as an irresistible compulsion that does not reduce autonomy (Dubljević 2013).

According to Dubljević, in democratic societies, the law as a normative structure draws on moral-political concepts (such as autonomy, as opposed to metaphysical concepts, such as “free will”) and makes binary distinctions that are grounded in specific gradual capacities such as self-control (Dubljević 2016). It also uses specific constructs such as the standard of “reasonableness” to determine when gradual capacities reach a certain threshold.

The crucial point in applying Dubljević’s view to cases of bvFTD would be to consider whether they are able to resist “mild compulsions,” to form “long-term aims,” as well as to “show commitment” to them. Let’s try to apply all three of these views specifically to the cases of early stages of bvFTD.

Wide Reflective Equilibrium of Principles of Autonomy in the Case of bvFTD

So, do these re-conceptualizations of autonomy do a better job at providing explicit rules to accommodate our intuitions and offer a more nuanced guidance in cases of individuals affected by bvFTD? It will be remembered that the application of the reflective equilibrium (even for only one theory) comprises of an interactive process: principles codify existing moral practices (and accompanying intuitions) and inform decision-making in novel situations and cases, where there is ambiguity or a clash of intuitions and principles. The method implies a to-and-fro process of reconsidering principles and revising intuitions until a stable, coherent set (or equilibrium) emerges.

Thus, all three re-conceptualizations provide a promising starting point in terms of a principled normative

guidance. For instance, it could be the case that bvFTD patients are no longer able to appreciate their “critical interests,” that they have lost that basic part of their personality that allows for the “capacity to value” and that they are more akin to minors in terms of resisting “indirect coercion” and “mild compulsion.” However, the determination of specific actions that are not autonomous is not obvious in these cases. This is because all three re-conceptualizations of autonomy explicitly prescribe erring on the side of autonomy:

[A]dult citizens of normal [cognitive] competence have a right to autonomy, that is, a right to make important decisions defining their own lives for themselves. (Dworkin 1993, 222)

Anyone who has a conception of himself, a set of ideals that he wants to live up to and in virtue of which he assesses his own value, is no doubt a valuer. (Jaworska 2006, 92)

All adult human beings are assumed to be responsible for states of affairs their bodies have causally initiated unless it can be proven that they were coerced by an outside force or compelled by an inside force *they could not endorse and incorporate in their long-term rational life-plan after a period of informed critical reflection.* (Dubljević 2013, 46).

BvFTD patients seem to retain most if not all cognitive capacities, endorse the illegal and immoral actions they make (and perhaps even start valuing them), and appear not to be concerned with any long-term plans. Even though both Alzheimer’s and bvFTD are cases of dementia, the ways in which individuals are affected is very different,³ and so there can be no direct application of Dworkin’s or Jaworska’s views without additional effort in tweaking them. This is most clear in terms of retaining personality or expressing character: Alzheimer’s patients could be viewed as the same people they were, just with cognitive deficits (at least in the early stages), whereas bvFTD patients are no longer their old selves in terms of character or values. The same holds for the application of Dubljević’s view, since there is an important difference between addiction and bvFTD: most addicts are aware that their substance abuse is ruining their lives but merely lack the willpower

³ Even though Alzheimer’s disease (AD) and FTD share certain symptoms, the onset and progression are different. Thus, socio-moral decision-making deficits do occur in AD but at a much later stage. I am grateful to an anonymous reviewer for prompting me to make this clear.

to resist and thus embrace even compulsive tendencies that help them overcome addiction.⁴ Unlike Alzheimer’s patients and addicts, most bvFTD patients are not concerned about their condition and may even be happy in their disinhibition. For instance, Mendez’s report (2010) of the elderly woman quoted above also notes that

[She] frequently made puns and burst into laughter. Yet, her concern for others was generally decreased. For example, when asked about the recent death of a close relative, she verbally expressed sadness and then quickly lapsed into laughter and light-hearted responsiveness. (Mendez 2010, 319)

The characteristics of bvFTD summarized above present serious objections preventing the use of subjective report, commitment to current compulsions, or claims about unqualified ability to value or quality of life as standards for ascertaining autonomy. However, the lack of planning and loss of practical appreciation for justifiable values might be exactly what is missing to have full autonomy and might constitute reasons for curbing certain rights associated with autonomy. Thus, even though these re-conceptualizations of autonomy are geared towards Alzheimer’s and addiction as the model cases in application, they can be successfully applied in bvFTD cases as well to designate which actions are of concern and which are autonomous.

Then, of course, “normal cognitive competence” needs to be redefined to include socio-moral judgement, “capacity to value” needs to be redefined to exclude ideals such as sexually harassing more women than anyone else, and the ideal-typical degrees of compulsion need to be redefined in more general terms so as to be applicable in more cases than merely addiction. The

⁴ This is very clear in the example of Tommy McHugh: “... a heroin addict incarcerated for violent offenses ... addiction has persisted until a cerebral hemorrhage altered his personality. After suffering damage to frontal and temporal lobes, he was effectively cured of his addiction but he developed a *compulsive* interest in painting, sculpting, and writing. Unlike his previous condition (addiction), he is committed to his current compulsions, and claims that life is 100% better’. [...] [T]he idea of a rational life-plan clarifies the difference in these two compulsions. Namely, addiction to heroin cannot be incorporated into a long-term rational life-plan whereas compulsive artistic interest can” (Dubljević 2013, 48). Unlike addicts, however, bvFTD patients usually don’t see any issues with their anti-social behaviour, and feel that their lack of inhibition is basically liberating and good. In the words of one bvFTD patient “I’ve never felt better in my life” (see Dubljević 2019).

statements regarding default autonomy might be amended to state:

[A]dult citizens of normal [cognitive and socio-moral] competence have a right to autonomy, that is, a right to make important decisions defining their own lives for themselves. (Dworkin 1993, 222)

Anyone who has a conception of himself, a set of ideals [justifiable under fair terms of social cooperation] that he wants to live up to and in virtue of which he assesses his own value, is no doubt a valuer. (Jaworska 1999, 92)

All adult human beings are assumed to be responsible for states of affairs their bodies have causally initiated unless it can be proven that they were coerced by an outside force or compelled by an inside force *they [and others] could not [in principle] endorse and incorporate in their long-term rational life-plan after a period of informed critical reflection.* (Dubljević, 2013, 46)

Insisting on these additions is not counter to the general expectations of society. Indeed, prolonged development of cognitive and socio-moral judgement is a pre-requisite of attaining autonomy in the first place, notions of public autonomy and democracy provide accepted constraints to individual choice, and inclusion of others in the endorsability criterion not only makes the conception of autonomy more robust but also provides clear guidance.⁵

Finally, the ideal-typical degrees of compulsion can and should be restated in terms that are easier to apply in a range of cases, including bvFTD. They might be redefined as:

- a) Mild compulsion—defined in terms of lure of instant gratification or responding to environmental cues (e.g., absent-mindedly eating conveniently located sweets),
- b) Severe compulsion—defined in terms of long-term suffering in cases of deprivation (e.g. sexual gratification), and

- c) Total compulsion—defined in terms of complete physical need (e.g., the need to be hydrated).

In these terms, it is easier to explicitly demonstrate that bvFTD patients are more akin to minors than to adults; they lack the resources they once had for self-control and delayed gratification, and they lack the capacities for appreciating their critical interests in addition to making and updating rational life-plans in view of changing circumstances. The to-and-fro process of revision does not stop at amending moral principles: it should affect certain moral practices that are taken for granted and the accompanying intuitions. Here I sketch three such revisions of moral intuitions and practices in two specific “social system” environments (criminal justice and medical, respectively) and more generally in the social “life-world.”

Amending Moral Practices in the Criminal Justice System

In criminal proceedings, alterations in moral cognition might be considered before ascribing criminal responsibility (Mendez 2010) and defence attorneys may argue that their client’s ability to delay gratification (Mischel and Ayduk 2004) should be established before a judge (or jury) finds them guilty of offense. In fact, the legal system has responded to other model cases of loss of autonomy with the introduction of “diversion courts” arguably precisely because the “default” position can no longer be applied with a clear conscience. Namely, so-called “problem-solving courts” have been established throughout the United States and in many other Western countries. In recognition of the lack of autonomy in addiction, “drug courts” grew in the last few decades from only one court to a movement with thousands of courts in the United States (see Mitchell et al. 2012). The U.S. legal system also instantiated “mental health courts” as diversion interventions designed to engage defendants with mental illness in treatment in lieu of incarceration (Wolff, Fabrikant, and Belenko 2011). The underlying assumption is that lack of autonomy necessitates the shift in the criminal court’s focus from criminal processing to providing therapy.

⁵ Such guidance is familiar in the philosophical literature. For instance, Kitcher contends that “[d]esires are endorsable just in case there are possible environments in which they could be satisfied for all our fellows” and “... the desire to have adequate food is endorsable, whereas the desire to monopolize reproduction is not” (Kitcher 2011, 223).

Arguably, bvFTD is another clear case where autonomy is compromised, and establishing a diversion court for dementia would be justified on the grounds of principle of autonomy.⁶ Following a procedure similar to other diversion courts, such a “dementia court” would have four defining aspects: 1) a specialized docket of cases, in which defendants have (at least “possible”) dementia, 2) a collaborative and non-adversarial team comprised of a judge, prosecutor, defence attorney and a neurologist, 3) a link to a local treatment facility, and 4) some form of sanction for failing to comply with the court requirements (cf. Wolff, Fabrikant, and Belenko 2011). Ideally, most bvFTD cases would be addressed in “pre-plea” case processing (i.e., before they have been sentenced in a regular criminal court). In those cases, successful completion of court requirements would result in dropping of charges. However, some cases will undoubtedly be “post-plea.” In these cases, individuals with “possible” bvFTD would be admitted to the dementia court after conviction but before sentencing in the regular criminal court. In those cases, successful completion of the program would result in either probation or a sentence of time served.

Amending Moral Practices in the Medical System

Another difference resulting from this shift in understanding of autonomy in bvFTD should be in the way the medical system responds to the calls for help from distressed family members. BvFTD should immediately be considered and tested for (in individuals 55 and above), and medical experts—along with social workers, psychologists and bioethicists—should strive to procure assent from the affected individual so that pharmacological and non-pharmacological treatment and management of symptoms can start as early as possible (hopefully before the criminal justice system is involved). Additionally, the power of attorney and

⁶ As people with Alzheimer’s disease (AD) also exhibit failures of socio-moral judgement and commit crimes, and for reasons of expedience, I am not arguing for establishing a diversion court specifically for bvFTD. I presume that most of the cases will be from the bvFTD population, specifically because criminal behaviour is recurrent in bvFTD. For instance, a Swedish study reported instances of criminal behaviour in 14.9 per cent of AD patients and 42 per cent of FTD patients, whereas the criminal behaviour was recurrent in 56.4 per cent of AD patients and 89 per cent of FTD patients (see Liljegren et al. 2019). I am grateful to an anonymous reviewer whose constructive comments prompted me to consider socio-moral deficits in AD and generalization of findings of this article to how autonomy is embedded in the legal system.

proxy decision-maker should be secured well in advance of disastrous financial consequences. I use the term “assent” and not “informed consent” not because all steps of the informed consent process should not be followed in these cases but because the application of the re-conceptualized notions of autonomy demonstrates that bvFTD patients lack basic autonomy and therefore cannot give proper informed consent.

However, as Jaworska rightly notes, dementia patients are capable of giving assent for treatment and research purposes. Depending on the severity of the socio-moral decision-making deficits, bvFTD patients are akin to minors before legal emancipation and are deserving of respect at all times. The procedures for managing the affairs of individuals in early stage of bvFTD are not new; they were established for Alzheimer’s Disease and provide adequate guidance:

Guardians and conservators can be appointed by a court following a procedure to decide that an individual is indeed incapable of autonomous choice. Durable powers of attorney allow a person to set certain constraints on finances or medical care and to appoint someone to make decisions *before* becoming mentally incompetent. (U.S. Congress, Office of Technology Assessment 1987, 39; emphasis in the original)

The novelty in this proposal is that a different benchmark for establishing autonomy (or the lack thereof) be used: the amended re-conceptualizations of autonomy discussed here.

Amending Moral Intuitions and Practices in the Social “Life-world”

Last but not least, the application of the principles of autonomy for the case of bvFTD leads to a reconsideration of stigma associated with the condition. Arguably, many of the behaviours associated with the condition are moralized, shameful, and even deeply discrediting. The acknowledgement of deficits in autonomy could facilitate recognition that individuals living with bvFTD are not voluntarily engaged in inappropriate behaviour, that their family members do not share “flawed” character traits and that they should not be socially isolated. Indeed, current social perceptions that a life of a “demented individual” is not worth living provide value judgements that underpin social, moral, and even

political attitudes about healthcare expenses and allocation of medical resources. Social stigma, which is predicated on the assumption that certain behaviour is freely chosen, often involves interpersonal victimization or discrimination that may discourage the affected individual from seeking treatment (for a longer argument, see Dubljević 2019). The application of the principle of autonomy in bvFTD provides justification for de-stigmatization efforts: changing social attitudes and encouraging family members to speak out and seek help before financial damage is done.

This is what application of moral principles is all about: moral practices and intuitions are incoherent unless they are consistent in their treatment of similar cases. Society should not at the same time deny rights (and even social respect) to persons living with bvFTD based on their loss of autonomy and continue blaming and socially excluding them or their families. The morally right thing to do is to offer help and assistance in seeking and obtaining treatment and to avoid practices that discourage or postpone treatment.

Conclusion

Behavioural variant frontotemporal dementia patients do not feel concerned enough about their actions to be deterred from violating social norms. Their antisocial behaviours and lack of concern, guilt, or shame are most likely caused by the neurodegenerative process disrupting a neuromoral network localized in the frontal and anterior temporal lobes (Diehl-Schmid et al. 2013). They present a challenge for the traditional notion of autonomy and, by extension, for the medical and criminal justice systems, especially in early stages of the disease progression and in the slow-progression variant. The re-conceptualized notion of autonomy can, however, be sufficiently redefined to provide explicit rules and offer nuanced guidance in such cases. It is crucial to adequately and objectively assess the hallmarks of adult competence: the capacities of self-control, socio-moral decision-making, and for creating, appreciating, and updating rational life-plans and critical interests.

More research is needed to determine the specific deficits in moral cognition in bvFTD cases as well as to develop adequate means of evaluating the actual levels of volitional and life-steering capacity during psychiatric and neurological examination. Medical professionals, social workers, psychologists, legal experts,

and bioethicists need to work together with family members of bvFTD patients to develop and assess strategies for managing anti-social and imprudent behaviour.

Based on this analysis, certain social changes are warranted. At the level of the criminal justice system, diversion courts need to be instituted so that individuals living with bvFTD are not treated unjustly and harshly. At the level of the healthcare system, better integration of testing for and responding to instances of bvFTD need to be established. Finally, at the level of society, the condition should be de-stigmatized and individuals living with bvFTD and their family members should be supported rather than shunned.

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