JOURNAL OF MEDICAL LAW AND ETHICS; VOL. 8, NR. 1, 15-31, PARIS LEGAL PUBLISHERS © 2020

Fluctuating Capacity and the Strategic Role of Self-Binding Directives in Preserving Autonomy

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Abstract

The purpose of this article is to examine the concept of fluctuating capacity and its intricacies, identifying the issues that can inform the development of provisions in this area. The paper seeks to challenge the current binary approach applied in this context by showing that the lack of legal principles governing the concept of fluctuating capacity renders people in this category vulnerable to being denied autonomy. It proposes a conceptual definition for the determination of fluctuating capacity and suggests the use of self-binding directives as a measure to overcome the setbacks of the binary approach. The paper also proposes expanding the application of self-binding directives to include a wider scope of disorders with episodic features, adding to the debate on the autonomy and rights of people with bipolar disorder. The ethical justification for adopting self-binding directives in this context is the safeguarding of autonomy when individuals prefer to extend their autonomy beyond moments of incapacity.

Introduction

Fluctuating capacity is a generic term used to describe the variability associated with changes in decision-making capacity. Such changes are characteristic of the onset and recovery from diseases with episodic manifestations affecting decision-making capacity. These cognitive fluctuations[1] occur on a cyclical basis, with periods of remission and full capacity alongside periods wherein decision-making capacity is either temporarily lost and then recovered, or is intermittent. The recurring manifestation of these cognitive fluctuations can influence a person's decision-making and evaluative abilities and threaten their autonomy by creating distorting effects, impacting their values and preferences. The fluctuations also challenge the current binary approach to capa-

* DOI 10.7590/221354020X15922956412979 2213-5405 2020 Journal of Medical Law and Ethics

1 Cognitive fluctuations are broadly defined in the sense that they can affect multiple cognitive domains, such as attention and vigilance, behavior, and functional abilities; S Varanese, 'Fluctuating Cognition and Different Cognitive and Behavioural Profiles in Parkinson's Disease with Dementia: Comparison of Dementia with Lewy Bodies and Alzheimer's Disease' (2010) 257 J Neurol 1004-11.

city/incapacity, creating difficulty in the legal handling of capacity, where capacity appears on a continuum.[2]

Currently, exploration and discussion of fluctuating capacity in the literature remains limited, driving the need to consider the issue in relation to the mental capacity law and in relation to the increasingly challenging application of the binary approach in this context.[3] The law's endorsement of autonomy requires a presumption in favour of capacity,[4] which is now statutorily endorsed in the Mental Capacity Act (MCA) 2005. The MCA, which governs a wide range of decisions,[5] provides a framework to deal with people lacking the capacity to make particular decisions.[6] A binary approach is used to differentiate between those who are deemed to have capacity – seen as the manifestation of individual choice and self-determination[7] and, as such, respected as making autonomous decisions – and those deemed to lack capacity, where decisions will be made on their behalf based on what is perceived to be in their best interests.[8] The result is a constructed binary approach that ignores possible variation in capacity and limits the endorsement of autonomy for those who do not fit neatly into the binary model.

This article argues that while the MCA 2005 retains some potential to address fluctuating capacity, it does not provide an adequate framework in relation to decision-making for people who fall into this category. The paper suggests the need to re-examine the concept of fluctuating capacity, and advances the argument that where a person's decisional capacity lies on a continuum, adopting

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2 See L Shelford, *Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind* (JS Littell 1833) 23; Re T 'Adult: Refusal of Medical Treatment' [1992] 3 WLR 782, 796.

3 The dissatisfaction with the dividing line drawn by the Mental Capacity Act 2005 is growing and the problematic nature of this approach was recognised by the House of Lords in their Select Committee (2014) post-legislative report of the statute session 2013-14, para 3 and the UN Committee on the Rights of People with Disabilities in their General Comment - CRPD/D/GC/1, General Comment No. 1 (2014) Committee on the Rights of Persons with Disabilities: Article 12, Equal Recognition before the Law, (OHCHR 2014); C Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue and Autonomy* (Cambridge University Press 2017); M Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24(3) Medical Law Review 318; J Herring & J Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act' (2015) 35(4) Legal Studies 698; L Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) 40 International Journal of Law and Psychiatry 80.

4 MCA 2005 s 1.

5 From the trivial of day-to-day decisions such as what to eat, what to wear and where to go, to the more complex such as medical treatment decisions, residence decisions, decisions as to contact with particular individuals, marriage and capacity to consent to sex.

6 MCA 2005 s 1(2).

7 'Self-determination' describes the right of an individual to determine what is done to them. The terms 'autonomy' and 'self-determination' are used intermittently or independently in this paper to mean the autonomous agent's perspective, to shape one's self or one's circumstances in a specific way, i.e. self-governance.

8 MCA 2005 s 4.

self-binding directives will offer a measure to overcome some of the setbacks of the binary approach in this context.

The article draws on the scholarly work of Gergel and Owen,[9] in which they provided a framework for constructing self-binding directives constituting a treatment request for people diagnosed with bipolar disorder as a way for them to deal with episodic crises and fluctuating capacity. This article argues the need to extend the application of self-binding directives to a wider range of disorders with episodic features to encourage acts of self-determination and to increase the scope of choices available for those whose capacity is not completely lost. It starts by proposing a conceptual definition of fluctuating capacity, highlighting the characteristics for such a determination. Once the requirements are satisfied, the treating clinician suggests a pre-commitment to a self-binding directive for the anticipated health crisis. The measure replaces the application of the binary approach that may erroneously call capacity into question. The underlying ethical justification for advocating the use of the self-binding directive is the view that the directive respects, and gives effect to, a person's autonomy, while the measure aims at ensuring that the individual is more self-determining over time.

Background

The current concept of fluctuating capacity is limited. The term 'fluctuating capacity' is not identified in law, but has been used in practical guidance supporting legislation such as the MCA Code of Practice[10] and case law relating to mental disorders.[11] Fluctuating capacity is associated with changes in decision-making capacity, characteristic of the onset and recovery from various chronic disorders with episodic manifestations[12] in which decision-making capacity is intermittent. These cognitive fluctuations follow a cyclical pattern, where the shift into a cycle is usually a gradual process of escalation with periods of remission and full capacity between. They can manifest during

9 T Gergel & G Owen, 'Fluctuating Capacity and Advance Decision-Making in Bipolar Affective Disorder – Self Binding Directives and Self-Determination' (2015) 40 International Journal of Law and Psychiatry 92-101.

10 MCA 2005 Code of Practice ss 4.26 and 4.27.

11 *R v C* [2009] UKHL 42.

12 The list of chronic diseases encompasses various diseases from neurodegenerative, degenerative diseases and neurocognitive diseases such as early onset of dementia, Alzheimer disease, Parkinson's disease, motor neurone diseases, multiple sclerosis, to cardiovascular diseases, bipolar disorder, migraine that are related to normal ageing or those that are genetic or hereditary such as Huntington's disease, mental health diseases amongst other chronic disorders such as diabetes to name a few.

various stages of a chronic disease, mental health condition, or neurocognitive or degenerative disease.

Symptoms of cognitive fluctuation can vary in intensity,[13] alternating between episodes of impairment, lucidity and capable task performance.[14] Given that onset and recovery are typically gradual and occur on a cyclical basis, it is very difficult to judge the exact moment at which decision-making capacity is lost or regained, often creating uncertainty as to whether the person can make valid decisions.[15] According to Escandon and colleagues,"the absence of a standardised way of assessing the presence of fluctuations makes it difficult to determine how much interference with cognitive performance can be directly attributed to fluctuations".[16] It is as well unclear to what extent the presence of fluctuations impairs decisional abilities. These abilities are dimensional with patients have varying degrees of decisional abilities that can be assessed.[17]

In theory, section 4(3) of the MCA 2005 acknowledges that the capacity to make a particular decision can develop or fluctuate, and requires assessors to consider whether the decision could be taken at a later point when a person may have gained or regained capacity.[18] However, at the crucial point, a binary approach is used where a patient either passes the capacity test or lacks the capacity to make a particular decision, drawing a sharp divide between those who are competent and those who are not. For those whose capacity is associated with one or more of the symptoms of a disease, the challenge consists of whether a person with intermittent decisional capacity has sufficient capacity to make a particular choice, thereby demonstrating a level of capacity that ought to be respected. This question continues to cause difficulties for the legislature when it comes to the particularities and challenges that need to be addressed in this context in theory and in practice.

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13 Symptoms can be described as periods of behavioural confusion, inattention, incoherent speech, mania, depression, impulsive behaviour, spending, paranoia, amongst other symptoms. A Escandon, N Al-Hammadi & J Galvin, 'Effect of Cognitive Fluctuation on Neuropsychological Performance in Aging and Dementia' (2010) 74(3) Neurology 210-217; J Bradshaw et al, 'Fluctuating Cognition in Dementia with Lewy bodies and Alzheimer's Diseases is Qualitatively Distinct' (2004) 75(3) J Neurol Neurosurg Psychiatry 382-387.

14 A Escandon, N Al-Hammadi & J Galvin, 'Effect of Cognitive Fluctuation on Neuropsychological Performance in Aging and Dementia' (2010) 74(3) Neurology 210-217.

15 S Kim, J Karlawish & E Caine, 'Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons' (2002) 10 Am J Geriatr Psychiatry 151-165.

16 Supra 14 A Escandon et al.

17 Decisional abilities is the four abilities model that include the abilities to understand, appreciate, reason and express a choice included in the mental capacity test which uses a two part test to assess a person's capacity to make a decision.

18 MCA 2005 s 4 (3).

A conceptual definition

Generally, there is considerable complexity and difficulty when it comes to interpreting and applying the concept of fluctuating capacity, and it requires substantially greater clarity. Conceptually, there is no agreed definition of the term 'fluctuating capacity' in the literature, and it is generally difficult to categorise capacity when cognition is found to oscillate between moments of impairment and moments of lucidity. Similarly, there is no agreed definition of what constitutes fluctuating capacity; however, it can be argued that the main challenge with determining fluctuating capacity is not the lack of definition or the lack of pathology, but rather its legal handling. The evident lack of definition and clarity provides a platform for a need to develop a conceptual definition that will assist in addressing some of the observed challenges. In discussion of study findings, Kim and colleagues agree that"inconsistent definitions can lead to confusions".[19] To address this gap, this article proposes the following definition for consideration:

Fluctuating capacity occurs when mental capacity is temporarily insufficient, influencing a person's decision-making ability, causing them to behave in an unfamiliar or uncharacteristic manner, and so subjecting themself or others to the risk of harm.

The proposed definition highlights three characteristics for a determination of fluctuating capacity. The first point involves a person whose capacity is doubtful or insufficient. The second point involves a person who seeks to engage in an uncharacteristic behaviour that would be inconsistent with the values upon which the person's life was built. The third point involves a person that chooses to engage in an activity that carries a significant risk of harm to themself or to others where harm in this context, as considered by Bottoms and Brownsword, may take into account"the degree of risk to the person, the risks to others, and the indirect consequences to society".[20] Additionally, the authors suggest further relevant factors that constitute the conception of harm relate to the"seriousness, immediacy and the certainty of possible harm".[21] As this definition proposes, what is important is that whilst capacity is the main locus of evaluation, the definition is focused on the characteristics that evolve from cognitive fluctuations, leaving the capacity/incapacity framework outside the official margins of the assessment.

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19 Supra at 15.

20 A Bottoms and R Brownsword, 'Dangerousness and Rights' in J Hinton (ed.) *Dangerousness: Problems of Assessment and Prediction* (Allen and Unwin 1983) 9; D Strang, D Molloy & C Harrison, 'Capacity to Choose Place of Residence: Autonomy vs Beneficence?' (1998) 14(25) J. Palliative Care 26; see also J Werth Jr, 'Requests for Physician-Assisted Death: Guidelines for Assessing Mental Capacity and Impaired Judgment' (2000) 6 Psych. Pub. Pol'y & L. 348.

21 ibid.

In English law, the standard legal approach to capacity provides that a competent person is free to engage in harmful activities if he or she wishes and their decision must be respected. The person is also free to change their mind about issues and to take up new activities and interests, even if previously they would not have adopted them. However, according to Childress, sudden changes and desires are not always protected under autonomy if there are reasons to believe that they contradict the values the person has held during their life.[22] Furthermore, Bruce Miller considers that the authenticity of a choice or an action is congruent"with the attitudes, values, dispositions and life plans of the person".[23] Hence, the consistency or inconsistency of a present choice with a person's life plans may help determine whether the decision is genuine.

Under the MCA, the response is that where a person approaches a decision with impulsivity and irrationality, or when they choose to engage in an activity that carries a significant risk of harm, or abandon a long-held belief, the decision provides the basis to re-examine that person's decision-making capacity. Where the decision to take the risk is shown to reflect beliefs that represent a genuine part of the person's life vision, is an expression of identity and is made with a full understanding of the consequences, the decision can be justified and respected.[24] Where the decision does not reflect these values and it is uncertain whether the decision has been considered with a full understanding of the consequences, less weight may be attached to the decision, since it does not reflect an autonomous decision based on the person's values and preferences.[25]

Herring and Wall consider that while both decisions deserve respect, they do not justify the same level of respect.[26] In this respect, the concern lies with the current legal approach where the legal responses reflect that the judicial system commonly provides special powers to intervene in the medical care and treatment of those whose decision may cause them serious harm. This, in turn, will interfere with a person's ability to exercise autonomy subsequently: unless there is certainty that the decision is a richly autonomous one, that decision will be weakly protected under the 'best interests' approach. In an attempt to overcome some of the setbacks of the binary approach in this context, the alternative approach is to set out a prior directive in anticipation of future periods in which capacity is temporarily lacking. The measure offers assistance

22 J Childress, 'The Place of Autonomy in Bioethics', *Hastings Center Report*, January/February (1990).

23 Bruce Miller, 'Autonomy and the Refusal of Life-Saving Treatment,' Hastings Center Report 11:4 (1981) 22-2.

24 J Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism? (2007) 15 Health Care Analysis 235.

25 J Herring & J Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act' (2015) 35(4) Legal Studies 698.

26 ibid.

for those who are not found to lack mental capacity under the Act but who can be considered vulnerable to its protective measures, justified as safeguarding.

The concept of self-binding directives

Currently, the Netherlands is the only country that has introduced self-binding directives into its mental health legislation.[27] Elsewhere, there are models of advance decisions recognised to some degree within legislation, but they are limited to treatment refusal.[28] In England and Wales, the provisions of sections 24-26 of the MCA 2005[29] acknowledge advance decisions to refuse life-prolonging treatment, but no clinical or legal provision to support any form of advance decision to request treatment[30] exists. These advance decisions, drafted to cover future decisions, are restricted to refusals applicable to manage end of life situations and disorders such as Alzheimer's disease or brain injury, where fluctuating capacity is not characteristic.

A self-binding directive (SBD) concerns the drafting of a self-imposed directive to cover future decisions at a time when a person temporarily loses the ability to make treatment decisions. The general SBD model is known as a 'Ulysses contract', 'self-binding directive', 'pre-commitment'[31] or 'voluntary

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27 Wet Bopz Act (Special Admissions Act in Psychiatric Hospitals) ss 34a-34p. <wetten.overheid.nl/BWBR0005700/2018-08-01#HoofdstukIII> (accessed 14th April 2019).

28 The right to refuse life-sustaining treatments was established for people with capacity in *MS B v An NHS Hospital Trust* [2002] EWHC 429 (Fam).

29 MCA 2005 ss 24-26.

30 Generally, advance directives requesting treatment are considered problematic and subject to clinical discretion. Patient's role in treatment request was deliberated in *Burke v GMC* [2004] EWHC 1879 where Mr. Burke had challenged the GMC's guidelines on withholding and withdrawing life prolonging treatments. The court established that the right to request life-prolonging treatment in advance decisions needs to be considered in light of patient's autonomy, clinical judgment and existing law. The deliberation in the matter also relates to its impact on the distribution of resources where the rights of other patients are considered for the provision of healthcare to all who need it in addition to the determination of exceptionality in some cases. The demand for treatment is also considered as potentially having destabilising effects on healthcare practices and regulations as argued in M Shepard, 'Fallacy or Functionality: Law and Policy of Patient Treatment Choice in the NHS' (2016) 24 Health Care Analysis 279-300. As such, SBDs differ from ADs in that the patient is not requesting life prolonging treatment and capacity is expected to recover at a time in the future. The comparison in this situation is not relevant as the specifics of the situation differ.

31 The name 'Ulysses contract' refers to Homer's example of Ulysses instructing his crew to bind him to the mast of his ship before they sailed past the captivating sirens and to ignore his requests for release by putting melted wax in the ears of his crew, so they could not hear the singing, nor his requests for release. J Elster, *Ulysses and the Syrens, Studies in Rationality and Irrationality* (ed. 1984, Cambridge University Press). Thus Ulysses was able to enjoy the beautiful singing of the sirens without suffering the disastrous results that would normally have followed. G Widdershoven & M Smiths, 'Ethics and Narratives' in R Josselson ed. *Ethics and Process in the Narrative Study of Lives* 4 (Sage 1996) 275-87; R Berghmans, 'Coercive Treatment in Psychiatry' in R Chadwick, *Encyclopedia of Applied Ethics*' (Academic Press 1997) vol 1, 535-42; It also has been named as the 'voluntary commitment contract' R Dresser, 'Ulysses and the Psychiatrists: A Legal and Policy Analysis of the Voluntary Commitment Contract' (1982)

commitment contract',[32] and is a contract by which the person commits to a future course of action by giving prior authorisation to treatment intervention and consent to override a potential refusal at a later time when they become incompetent. At that point, a so-called precedent autonomy[33] is executed, wherein autonomy is regarded as an extension of a competent person's right to autonomy. It requires that the person's past decisions about how to be treated in case of incompetence be respected, even if those wishes contradict the desires they have at that later point.[34]

The relevance of the SBD becomes increasingly significant in relation to cases of chronic illness with episodic features: here, a binary approach does not engage with the core of the problem, leaving people with fluctuating capacity in a position wherein they are deemed either to have capacity or not. In these situations, the SBD shifts the focus away from tests for capacity, instead promoting flexibility and autonomy. The directive acts as a helpful strategy that authorises the use of pre-approved treatment[35] when an anticipated health crisis arises, at an earlier point than is conventionally the case. By anticipating that the patient will be unable, even with support and help, to prevent themself from exhibiting damaging behaviour at some point in the future and at a time when their decision-making capacity is impaired, the SBD will be invoked to authorise the pre-approved compulsory treatment once the requirements are satisfied, even in case of that person's refusal.[36] This approach enables the person to exercise control over future decisions, preserving their autonomy and reinforcing the exercise of self-determination.

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16 Harvard Civil Rights - Civil Liberties Law Review 777-854; T Howell, R Diamond & D Wikler, 'Is There a Case for Voluntary Commitment?' in T Beauchamp & L Walters, *Contemporary Issues in Bioethics* (2nd edn, Wadsworth Publishing Company 1982) 163-168; Different authors have proposed such contracts as instruments of 'consent-in-advance', 'precommitment' or 'advance treatment authorization'. D Brock, 'A Proposal for the Use of Advance Directives in the Treatment of Incompetent Mentally Ill Persons' (1993) 7 (2-3) Bioethics 247-256.

32 R Dresser, 'Ulysses and the Psychiatrists: A Legal and Policy Analysis of Voluntary Commitment Contract' (1982) 16 Harvard Civil Rights – Civil Liberties Law Review 777-854.

33 Precedent autonomy is the notion that an individual's preferences when autonomous trump their preferences when lacking autonomy and that this can extend self-determination to incapacity. R Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Vintage Books 1990) 226.

34 ibid.

35 Treatment decisions include certain aspect as non-treatment related elements of care and management of affairs when the person is ill and the desire to involve family members or carers.

36 S Gevers, 'Advance Directives in Psychiatry' (2002) 9 European Journal of Health Law 19; A Halpern, & G Szmukler, 'Psychiatric Advance Directives: Reconciling Autonomy and Non-Consensual Treatment' (1997) 21 Psychiatric Bulletin 323-327; B Sheetz, 'Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility' (2006) 40 The University of Michigan Journal of Law Reform 401; I Varekamp, 'Ulysses Directives in The Netherlands: Opinions of Psychiatrists and Clients (2004) 70 Health Policy 291-301.

For the SBD to be legally binding, its moral authority rests on capacity being confirmed at the time of its drafting and the directive being autonomously considered by the patient. It is perceived as part of the communication process between the patient and the treating doctor in light of the patient's medical history. It is therefore a tool that enables the treating doctors to get an insight into their patients' views and preferences and to deliberate on the best course of action to be taken in cases where treatment choices are to be considered and patients are unable to express their views.

The proposed SBD model follows some of the requirements suggested in Gergel and Owen's[37] model, developed to assist people with bipolar disorder. Their model is also similar to the Dutch model of self-binding directives[38] that came into force in 2008. The Dutch model consists of a number of legal requirements and safeguards that limits the scope of its application to patients with mental health conditions.[39] In the Dutch model, the directive can only be authorised by a court order, known as a self-binding authorisation (SBA).[40] It can only be enforced on patients admitted to a psychiatric hospital, binding them involuntarily to a pre-approved treatment, and applies only to a treatment that does not exceed six weeks. The element of 'risk of harm' is not a requirement for the court to issue an SBA. The order is issued as a timely intervention to prevent the patient from potentially engaging in an act that may constitute harm to themself or others. Moreover, the directive does not apply to people with intellectual disability or to the elderly with cognitive impairment.[41] It is valid for one year, and can be renewed yearly.

While the model suggested in this paper features some of the requirements in the model advanced by Gergel and Owen,[42] other original requirements are newly introduced for consideration. The suggested model offers a different role in terms of, first, establishing the directive's eligibility criteria, wherein its scope is not limited to a specific treatment or a specific health condition. Rather, the directive is relevant to a broad range of medical conditions in which cognitive abilities can be compromised, affecting personal behaviour and character, and increasing the risk of diminished capacity. Second, the SBD must be drafted

37 Supra at 9.

38 The Dutch self-binding legislation came into force in January 1, 2008. It was introduced in the Wet Bopz Act (Special Admissions Act in Psychiatric Hospitals) ss 34a-34p. <https://wetten.overheid.nl/BWBR0005700/2018-08-01#HoofdstukIII>.

39 Wet Bopz Act, Articles 34a-34p; <https://wetten.overheid.nl/BWBR0005700/2018-08-01#HoofdstukIII>.

40 The self-binding legislation is a central element of the regulation and encompasses two types of directives. One type is for the admission and the treatment (the admission can only take place on the basis of a self-binding authorisation by the court), and the other type is enforceable for treatment only in cases where the patient has already been admitted to hospital on a provisional detention authorisation or an interim order.

41 Supra at 36.

42 Supra at 9.

during a lucid interval in which the test for capacity is met. The drafting is informed by medical judgement and the patient's own evaluation of when they consider themself to be at potential risk of harm and when treatment interventions could be introduced in such cases.

Furthermore, the proposed framework illustrates the way in which a much more nuanced approach to dealing with fluctuating capacity is required than one which focuses on the application of the binary approach and its outcome. The framework highlights the need to emphasise the nature of fluctuating capacity and its impact upon the person and their decision-making capacity. The approach strongly prioritises attention to particular behaviour and symptoms, and the need to frame appropriate responses tailored to the individual to achieve control over their own decisions. The provisions include the person's own evaluation of when they consider themselves to be at potential risk of harm and when treatment interventions could be introduced in such cases. For the SBD to be justified and upheld, the following process is suggested for consideration.

1. The patient's capacity must be established at the time of the drafting of the directive. The capacity assessment test is to be carried out by the treating doctor or psychiatrist involved in the patient's care during a period in which the patient is in remission.
2. The SBD is structured and informed in light of the patient's medical history related to the medical condition at issue. A doctor-patient evaluation of when the directive should be invoked will be based on prodromal symptoms[43] and particular behaviours that would indicate the loss of decision-making capacity.
3. Evaluation of the risk of harm relies on the patient's account of their medical history related to their health condition. The patient identifies a set of behaviours, described as prodromal indicators, early signs and symptoms of a potential temporary loss of capacity, or signs of alteration in cognition. Further conditions may be specified, such as how many of these behaviours must be observed before the directive is invoked.[44]
4. The assessment will allow evaluation of the patient's future healthcare needs and appropriate treatment based on the relevant information according to the patient's medical history.[45] The clinician will suggest recommended treatment/s to be decided upon, a decision that must be informed and free of coercion. The SBD could also suggest the time for which the treatment should be given; the preferred treatment options where first line treatments intervention fail; behavioural indicators which could lead to

43 In medicine, a prodromal is an early sign or symptom or set of signs and symptoms indicating the onset of an attack or a disease.

44 Supra at 31.

45 ibid; I Gremmen et al, 'Ulysses Arrangements in Psychiatry: A Matter of Good Care?' (2008) 34 (2) Journal of Medical Ethics 77-80.

the discontinuation of recommended treatments; and the indicators that the patient has recovered their decision-making capacity.[46]

5. Once the behaviours specified in the directive manifest themselves and are recognised as triggering factors, suggesting the forthcoming health crisis, the directive will be invoked and the patient should be offered the pre-approved compulsory treatments indicated in the directive.
6. Details of the treatment interventions proposed and agreed upon in the SBD are also described.
7. The patient is free to revoke or revise the SBD at any time when capacity is present.[47]
8. A directive is not applicable if: (a) the treatment required is not specified in the SBD; (b) any circumstances specified in the directive are absent; or (c) there are reasonable grounds to believe that circumstances exist which the patient did not anticipate at the time of its drafting that would have affected the patient's decision had they been anticipated.[48]
9. Finally, a statement of values detailing the wishes or priorities underpinning the decision should be noted.

Drafting an SBD requires a discussion between the patient and their treating doctor or psychiatrist to discuss the early signs of a specific health condition. In the discussion process, decision-making capacity is assessed on the basis of the patient's understanding that they prospectively revoke their right to refuse treatment in the event of a health crisis and commit to the intervention based on the SBD that will be invoked as indicated. The discussion covers the potential risk of harm to be prevented, the triggering factors, the types of behaviour indicating the anticipated health crisis, and the treatment interventions necessary should these symptoms express themselves, even if the patient refuses treatment.[49]

The aim of the intervention is to prevent the person from engaging in damaging and risky behaviour, putting themself or others at risk of harm as they deteriorate. When activated, the directive binds the person to their precommitment by giving effect to their precedent autonomy, reflecting previous wishes and preferences communicated in the SBD connecting their beliefs and values to the prospective decision-making, unless the person has sufficient capacity to refuse its enforcement. The directive's moral authority derives from

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46 ibid.

47 R Berghmans & M Der Zanden, 'Choosing to Limit Choice: Self-Binding Directives in Dutch Mental Health Care' (2012) 35 International Journal of Law and Psychiatry 11-18; Supra at 28.

48 This provision is captured in the MCA 2005 s 25 (4)(c).

49 G Widdershoven & M Smiths, 'Ethics and Narratives' in R Josselson ed. *Ethics and Process in the Narrative Study of Lives* 4 (Sage 1996) 275-87; R Berghmans, 'Coercive Treatment in Psychiatry' in R Chadwick, *Encyclopedia of Applied Ethics*' (edn 1, Academic Press 1997) 535-42.

a prior respect for the person's autonomous choice to extend their decision-making with the same authority as a contemporaneously made autonomous decision.

Advantages of self-binding directives over advance directives in fluctuating capacity

The difference between self-binding directives and advance decisions essentially relies on two factors. The first factor depends on whether capacity will be recovered at some point in the future; the second relates to treatment request versus treatment refusal. Generally, advance decisions are restricted to treatment refusals and applicable to end of life situations, where capacity is not expected to recover and the patient requests the refusal of specific life-sustaining treatment in the future. SBDs offer a different advantage in which the directive only applies to situations in which the patient's capacity is expected to recover, where death or a comatose state is not envisaged.

Additionally, SBDs play an informing role in the assessment of capacity and in directing the pre-approved recommended treatment once capacity is judged to be temporarily lost, unlike the case with advance directives. Consequently, administering efficient treatment before or at the time of the onset of a health crisis in a specific health condition not only prevents the person from engaging in damaging and risky behaviour, but can promote shorter, less severe or more easily treatable episodes, which can lead to a greater overall stability and improved health outcomes.[50]

Furthermore, unlike the case with advance decisions, where there is a significant time gap between creation of the advance decision and when it comes into effect, with the consequent development of medical and technological advances in the meantime, SBDs are made in a context where significant information as to the kind of treatment available for the specific condition is available at the time the person creates the directive. This significant difference makes SBDs epistemologically superior to advance decisions in this context.[51]

It is also pertinent to reflect on the broader issue of personal identity and precedent autonomy in relation to advance decisions. Here, there is reliance upon the continuity or discontinuity of personal identity,[52] together with a loss

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50 Supra at 9.

51 This argument is similar in context to the argument advanced by Mary Donnelly on advance decisions in her book: M Donnelly, *Healthcare Decision-Making and the Law* (Cambridge University Press 2011) 223.

52 D Parfitt, *Reasons and Persons* (Oxford University Press 1984); R Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 (3) Ariz. L. Rev. 373-405.

of decision-making capacity at the time the directive is invoked. In the context of SBDs drafted for people with fluctuating capacity, concerns over the issue of changing identity following the loss of capacity do not apply: permanent changes to personal identity are not relevant in this context, unlike in the debates on advance decisions in the context of irreversible illnesses where it could be argued that psychological continuity is so deeply interrupted that someone has become another person. Parfit takes the view that in such cases, advance directive should have no moral force in connection to the course of action to be currently taken than it would have had, had it been written by a stranger, friend or relative. A person who lost their capacity may have totally different interests to those they had as a person when they had capacity. It would follow from Parfit's theory, that there are no moral grounds to respect advance directives in such cases.

However, in the context of people with FC, the objection that the very process that renders the person incompetent and brings the SBD into play can destroy the necessary conditions for personal identity, thereby entirely undermining the moral authority of the directive, do not apply to the argument justifying the drafting and subsequent use of the SBD. This is because of the degree of psychological continuity present, which is a necessary condition for the preservation of personal identity: capacity is thus only temporarily lost and is regained with recovery. Here, the psychological aspect of personal identity is constituted by varying degrees of continuity between two temporally separate selves with regard to a person's personality, belief structure and desires, and the degree of the relationship between them may be a strong or weak but nonetheless still existing.

Hence, the value of the SBD lies to a large extent in the avoidance of treating a person with fluctuating capacity as an all-or-nothing affair, where the suggestion is that capacity is a matter of the degree to which personal identity exists beyond the moments of incapacity. Furthermore, because drafting the SBD requires the involvement of the treating doctor or psychiatrist, their involvement will not only influence the directive's efficacy, but will also influence its endorsement should a conflict with the clinical judgement arise.[53] In that sense, doctors play a crucial role in drafting the directive:[54] their involvement ensures that the patient is competent and informed at the time of its creation, and the directive is drafted with sufficient specificity and clarity, increasing its effectiveness at the time of its implementation and making doctors feel more comfortable about upholding it.[55]

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53 C Vezzoni, 'The Legal Status and Social Practice of Treatment Directives in the Netherlands' (RUG 2005), cited in E Marike et al, 'Advance Directives in Dementia: Issues of Validity and Effectiveness' (2010) 22) Int'l Psychogeriatry 201-208.

54 C Auckland, 'Protecting me from my Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia' 0 (2017) Medical Law Review 1-25, 12.

55 R Schiff et al, 'Living Wills and the Mental Capacity Act: A Postal Questionnaire Survey of UK Geriatricians' (2006) 35 Age and Ageing 116-121.

Grounds for invoking self-binding directives and its moral authority

Given the importance accorded to the principle of autonomy,[56] the ethical basis for adopting an SBD for persons with fluctuating capacity is the notion that the directive would offer them a sense of control over their illness by affording them greater responsibility for their care. The exercise of control over one's own decisions gives effect to precedent autonomy. It requires that a person's past wishes about how to be treated in case of incompetence be respected, even if those wishes contradict their contemporaneous wishes.[57] Appealing to precedent autonomy is essentially normative and relates to what the person established as their objectives, goals and values when they had capacity and according to which they would like to direct their life.[58] The experience of fluctuation in capacity would be considered interruptive of these objectives, while holding an SBD would serve as a device to secure the continuity and survival of precedent autonomy when the latter seems to be threatened by the interruptive events.

Generally, concerns about the applicability of the directive arise predominantly because of the need to satisfy the validity and applicability requirements to the reasonable certainty of the healthcare provider. Central to these concerns is establishing the moral authority of an SBD, which is linked to establishing capacity at the time of its drafting. The directive should highlight the need to structure an approach that responds to individually focused need and support, emphasising the nature of fluctuating capacity and its impact upon the person and their decision-making.

Therefore, the directive is not applicable if there is reason to believe that the pre-commitment was not autonomous at the time of its drafting, or when there are good grounds for doubting that the directive is an accurate reflection of what the patient would want. The directive is also not applicable if the treatment required is not specified in the directive,[59] if any circumstances stipulated in the directive are absent, or if there are reasonable grounds to believe that circumstances exist which the patient did not anticipate at the time of its drafting that would have affected their decision had they been anticipated. As such, its moral authority relates to establishing capacity at the time of its writing; identifying the triggering factors to enforce an SBD; the understanding of the

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56 T Beauchamp & J Childress, *Principles of Biomedical Ethics* (Oxford University Press 2001) 57-103. See also, HT Engelhard, *The Foundation of Bioethics* (2nd edn, Oxford University Press 1996); G Dworkin, *The Theory and Practice of Autonomy*, (Cambridge University Press 1988) 6; *Airedale NHS Trust v Bland* [1993] AC 789; *RT (Adult: Refusal of Treatment)* [1993] Fam 95.

57 G Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988) 228.

58 ibid.

59 MCA 2005 s 25 (4) (a).

person that they are removing their right to refuse treatment; and committing to the intervention that will take place when required. Finally, the manifestation of triggering factors prompts the enforcement of the directive in the anticipation and the prevention of harm.

On the one hand, it can be argued that if a person is allowed to make contemporaneous decisions, then they should be allowed to make anticipatory advance decisions.[60] With fluctuating capacity, given that the passage of time is continuous, it is possible to make a prospective decision. It can also be argued that appealing to autonomy as legitimising a binding advance directive may depend on the justification underlying the right to self-determination. However, since SBDs are predicated on the basis of personal autonomy, and their authority applies to an individual if they are the same moral entity who created the directive, it can then be argued that if the same connectedness and continuity between past and present selves is present, the moral authority of the SBD can be considered legally binding.[61]

On the other hand, it is accepted that the SBD does not have the same authority as contemporaneous autonomous decision-making and, as such, is open to paternalistic rejection by others. This is because it is questionable whether the SBD goes far enough to promote self-determined prospective decision-making. While the degree of predictability and foresight required by law is to some extent covered in the SBD drafted for people with fluctuating capacity, the issue remains where the values and priorities of the person have changed and there is sufficient evidence that its enforcement is no longer justified. This could be the case in the presence of a condition that has changed significantly since the directive was drafted: upholding the directive cannot then be justified, given that it was made with no real understanding of the nature and consequences of the decision.

Consequently, for the directive to be justified, it should be drafted in sufficient detail to understand what the person's decision is in relation to a given set of circumstances, and with adequate information and understanding of the potential future condition, treatment options and commitment to the intervention. This is because enforcing an SBD cannot be respecting a person's autonomy if the decision is applied in circumstances that were not anticipated or intended by the person concerned. This situation is captured in the provision in section 25(4)(c) of the MCA in which the doctor or healthcare professional responsible for invoking the SBD is free to override it.

In a Ulysses contract, the justification for enforcing the contract is the intention to help individuals arrange their lives according to their wishes. In a similar

60 J Davis, 'How to Justify Enforcing a Ulysses Contract When Ulysses is Competent to Refuse?' (2008) 18(1) Kennedy Institute of Ethics Journal 87-106.

61 ibid.

vein, and using the same justification to enforce an SBD, a variant of what John Davis calls the "Defeater View"[62] is applied in this context, wherein a more commanding earlier wish defeats a less commanding future wish. Davis accepts that "where both wishes are competent and command respect under the principle of respect for autonomy, the earlier wish has more of whatever makes a wish command respect."[63] This justification is based on the role the person's past wishes play, as they can be evidence of what the person is likely to want in the future, promoting consistency. The mere existence of the SBD is good evidence of what the person used to want and may later want. Therefore, if the person wanted intervention in the past and has gone to the trouble of arranging the procedure through the process of drafting an SBD or similar, this process will promote consistency between the person's past and future circumstances over time and with reference to whether the outcome will be consistent with what that person wants over a long period of time.[64] However, although past wishes do not justify present intervention, they are not irrelevant to that justification, for they can be evidence of what the person is likely to want in the future.

It can also be argued that patients executing an SBD would be likely to have enough experience of their own medical history to be the best judges of whether enforcing the directive will produce the greatest consistency over time in terms of what they want and how their long-term wishes develop. Accordingly, this justification can account for the fact that the person's past wishes seem morally relevant based on the view that stable, long-term wishes command more respect and are likely to persist or recur in the future,[65] particularly if capacity is regained.

The aim of this kind of justification is to ensure that the individual is more self-determining over time. The justification is based on the fact that the person's circumstances are, over time, determined in a way that is as consistent as possible with their wishes, the way they would want them to be over time, regardless of whether they later give consent.[66] This does not compete with or override the person's autonomy, but rather promotes it. Here, the intervention is justified on the basis that doing so maximises the degree to which the person gets what they want in life by actively respecting the person's autonomy in pre-commitment cases. Limiting the use of such contracts to bipolar disorder will limit self-determination and choices for those whose cognitive capabilities are tem-

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62 The Defeater View is the view that a more commanding Time1 (original) wish defeats a less commanding Time2 (later) wish; J Davis, 'How to Justify Enforcing a Ulysses Contract When Ulysses is Competent to Refuse?' 87-106.

63 ibid 97-106.

64 ibid.

65 J Feinberg, *Harm to Self* (Oxford University Press 1986) 83.

66 This is not to say that interfering with a person's autonomy is allowed simply because it maximises the overall consistency over time or because the interference makes the person better off; good consequences do not justify interfering with someone's liberty.

porarily lost. However, enforcing the directive cannot be justified if there is sufficient evidence that the person has changed their mind – for example, if there is reason to believe that the person's present autonomous refusal will not change later on, or that the directive was established according to circumstances or medical options that have since changed.

Conclusion

Current legal and ethical conceptualisation of fluctuating capacity is limited. Fluctuating capacity is associated with changes in decision-making capacity characteristic of the onset and recovery from disorders with episodic features in which decision-making capacity is lost and then regained. Recurring cognitive fluctuation can influence a person's decision-making capacity, where capacity appears on a continuum, challenging the current binary approach adopted in the MCA. The currently use of the binary approach, where the person either passes the capacity test or lacks the capacity to make a particular decision, proves to be inadequate.

This paper has argued that where a person's capacity lies on a continuum, adopting an SBD would offer a measure to overcome some of the setbacks of the binary approach. By authorising pre-commitment to future treatment, the directive, influenced by the person's own views and assessment of their condition, allows a continuation of self-determination on the grounds that the decision protects the perceived wellbeing of the temporarily incompetent person by a means previously decided by that person, allowing that person to shape their life circumstances as they wish over time.

The value of the SBD therefore lies in avoiding treating a person with fluctuating capacity as either inappropriately competent or incompetent, and in the importance of safeguarding autonomy by extending a person's autonomy past the point of incapacity, superseding the 'best interests' decision-making approach. When drafted appropriately, the directive empowers individuals and gives moral authority to its application as the directive represents an autonomous decision. The involvement of the treating doctor in its drafting brings value to the directive and conveys confidence that capacity existed at the time of its drafting. In a general sense, the significance of the directive lies in the fact that it would offer the person with fluctuating capacity a sense of control over their illness by bringing into focus the importance of patients being able to make fully informed decisions about their care and treatment.

Declaration of Conflicting Interests

The author declared no potential conflicts of interests with respect to the research, authorship, and/or publication of this article.