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Fluctuating capacity and advance decision-making in Bipolar Affective Disorder – Self-binding directives and self-determination

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ABSTRACT

For people with Bipolar Affective Disorder, a self-binding (advance) directive (SBD), by which they commit themselves to treatment during future episodes of mania, even if unwilling, can seem the most rational way to deal with an imperfect predicament. Knowing that mania will almost certainly cause enormous damage to themselves, their preferred solution may well be to allow trusted others to enforce treatment and constraint, traumatic though this may be. No adequate provision exists for drafting a truly effective SBD and efforts to establish such provision are hampered by very valid, but also paralysing ethical, clinical and legal concerns. Effectively, the autonomy and rights of people with bipolar are being 'protected' through being denied an opportunity to protect themselves. From a standpoint firmly rooted in the clinical context and experience of mania, this article argues that an SBD, based on a patient-centred evaluation of capacity to make treatment decisions (DMC-T) and grounded within the clinician–patient relationship, could represent a legitimate and ethically coherent form of self-determination. After setting out background information on fluctuating capacity, mania and advance directives, this article proposes a framework for constructing such an SBD, and considers common objections, possible solutions and suggestions for future research.

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1. Introduction: the dilemma – the case of P

P is a 48 year old man who used to work as an electrician and has a diagnosis of Bipolar Affective Disorder. Since early adulthood he has experienced manic episodes, lasting a few months each, as well as one severe depressive episode, during which he attempted suicide by trying to jump off a bridge. He has now had approximately twenty hospital admissions. When well he tries his best to get on with his life, maintaining close contact with two grown up children and pursuing an interest in music. Both P and those who know him regard him as entirely well and 'himself' when in remission, but as a "different person" when ill/manic, whose behaviour is utterly uncharacteristic and associated with major harms to his relationships, self-esteem, property and affairs. During one episode, for example, his flat was stripped of all property including his bed and his car was taken.

P is intelligent and, when well, has very good insight into his condition and its consequences. He is persuaded that medication has helped to treat manic episodes, but not that adherence to medication is helpful in preventing further episodes. Although his family recognise the early

symptoms of an episode and often report these to his team, P is ordinarily resistant to treatment at these points and presents as in control of potential harms. Typically, he is considered below the threshold for compulsory treatment. This does occur, but is delayed until the situation has deteriorated significantly: "instead of them coming and getting me at the beginning, they'll leave me on the street, to get worse and worse, and worse and worse." In P's retrospective view, compulsory treatment has started too late.

P is desperate to stop this happening. He can clearly identify key prodromal indicators and, for the last three years he has repeated a wish for early intervention with compulsory treatment under Section 3 of England's Mental Health Act (1983)¹, as soon as the episode is beginning. P has repeated past experience of compulsory treatment. He says "I hate Section 3 anyway" and recognises that his proposed solution will be harrowing. Nevertheless, he maintains:

When becoming unwell treatment at home is not suitable for me. I need to be admitted to hospital under compulsory treatment, even if I seem to still have some control – otherwise I am likely to get overconfident and start getting involved with people and activities that disrupt my life.

Abbreviations: SBD, self-binding (advance) directive; PAD, psychiatric advance directive; DMC-T, capacity to make decisions concerning treatment.

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¹ This authorises compulsory admission and treatment for a period of up to 6 months at first instance with discharge possible at any point by the treating clinician or a tribunal.

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For P this would be a way of using his retrospective knowledge of his illness, when he has capacity, to minimise its enormous personal cost and take back control over his life.

P is attempting to use his surrounding social, clinical and legal framework to enable a form of self-determination known as a self-binding (advance) directive (SBD) or Ulysses Contract, in order to take control over his illness and limit the damage it causes. He stipulates early warning signs that should both be understood to indicate the need for an assessment for compulsory detention and treatment, and should inform the judgement which is made. These include fast speech, irritability, and grandiosity, along with behaviours like “bible-bashing,” going travelling and talking about philosophical questions. His stipulations are based on extensive past experience.

At present, however, the UK and nearly all other jurisdictions have no established clinical or legal provision to support this form of self-determination, even though both P and his clinicians can see that pre-binding to accepting treatment before major deterioration ensued could avert enormous damage. Like others with his condition, he faces a future of knowing that further episodes will most likely come, but being powerless to protect himself from their devastating effects.

Psychiatric advance directives (PADS) are the focus of increasing debate, being mooted as a mechanism to enhance self-determination within psychiatry, and discussion has intensified in the wake of the UN's Convention on the Rights of Persons with Disabilities (2008) (CRPD). However, though welcomed at a theoretical level, this is not reflected in practice and, even where provision exists, their use is uncommon (Backlar, 1998; Gallagher, 1998; Jeste & Saks, 2006, p. 624; Sarin, 2012; Srebnik & Kim, 2006; Swanson et al., 2003; Varekamp, 2004). A frequently cited aim of PADS in general is to reduce the need for coercion through, for example, improving crisis management recommendations based on patients' past experiences and preferences (Henderson et al., 2004; Khazaal, Chatton, Pasandin, Zullino, & Preisig, 2009; Swanson et al., 2008; Thornicroft et al., 2013). By contrast, a primary outcome of SBDs is to enable the individual to request introduction of coercive interventions in the earlier stages of illness, in order to prevent themselves from engaging in damaging and risky behaviour as they deteriorate (Gremmen, Widdershoven, Beekman, Zuijderhoudt, & Sevenhuijsen, 2008). Within the context of broad concerns about psychiatric coercion and current interpretations of the CRPD, which reject entirely judgements of incapacity and use of coercion (2014), this central coercive aspect of SBDs might seem problematic. Nevertheless, we contend that they could represent an ethically coherent means of enhancing self-determination which is consistent with the broadly worded aims of enablement and empowerment espoused within the CRPD itself.

We propose a form of SBD based on decision-making capacity for treatment (DMC-T) and argue that SBDs could have the potential to allow bipolar patients increased control and damage limitation. We will examine: the ‘fluctuating capacity’ characteristic of severe Bipolar Affective Disorder; the limitations of existing legal types of advance directives in this context; how to address associated rights-based and clinical difficulties. Unlike many discussions surrounding advance decision-making, which stem from an ethical and legal perspective, our starting-point is firmly rooted in the clinical context.

There is no perfect solution for the management of manic episodes, which, all too often, bring enormous personal damage and eventual deprivation of liberty — in the words of Gremmen et al. “coercion and care do not easily go together (2008).” SBDs will always involve a process of cost/benefit analysis, with major concerns on both sides. The notion of voluntarily committing one's conscious and often very lucid self to being treated involuntarily can seem shocking, especially to those unacquainted with the realities of living with mania. Even to clinicians, whose experience of patients is often dominated by times of crisis, it can seem inconceivable that a patient when well will have both the desire and ability to engage in a self-binding process. However, when well, those attempting to navigate the minefield of life with bipolar disorder

are left to struggle with both the damage from previous episodes and their fears for what future episodes might bring. An SBD, for those who wish to draft one, may well be the best available option, despite its costs (Gallagher, 1998). For the sake of individuals such as P, we argue that the legal and clinical community has a strong moral obligation to consider the feasibility of allowing the type of provision P requests (Gevers, 2002; Rosenson & Kasten, 1991; Sheetz, 2006; Winston, Winston, Appelbaum, & Rhoden, 1982).

2. Background

2.1. What do we mean by “fluctuating capacity” in bipolar disorder?

The term ‘fluctuating capacity’ is not recognised in statute, but has been used in secondary legislation, such as the Mental Capacity Act Code of Practice (Department of Constitutional Affairs, 2007) and case law². It is associated with changes in DMC-T characteristic of the onset and recovery from episodes of a psychiatric disorder such as mania within bipolar disorder. A typical time course showing change in symptoms and change in DMC-T is shown in Fig. 1.

Generally, DMC-T is lost as an episode worsens and then returns with recovery. Episodes occur on a cyclical basis, with substantial periods of remission and full capacity in between. Given that onset and recovery are usually gradual, it can be difficult to determine the exact moment at which DMC-T is judged lost or regained.

Loss of DMC-T is extremely common in mania, probably more so than for any other psychiatric condition, and is often regained in about a month (Owen et al., 2011). Several studies have concluded that the majority of manic inpatients are lacking in DMC-T (Beckett & Chaplin, 2006; Cairns et al., 2005a; Owen et al., 2008). The most recent of these, which involved clinical interviews and structured DMC-T assessment, reported that 97% of those admitted with mania to a psychiatric ward, whether formally or informally, had impaired DMC-T (Owen et al., 2008). Importantly, loss of DMC-T in mania associates strongly with two characteristics. These are loss of insight — a clinical construct depicting self-awareness of mental state change and illness (Owen et al., 2009); and loss of appreciation — a legal construct depicting ability to apply information abstractly understood to oneself. By contrast, within general medical hospital patients, it is most usually cognitive abilities which are affected (Owen et al., 2013). Thus, despite concerns which are frequently raised (Breden & Vollmann, 2004; Gallagher, 1998; Tan & Hope, 2008; Weller, 2013, pp. 8–9), it should not be assumed: that determining the lack of DMC-T in psychiatry is generally problematic; that evidence of good cognitive skills within mania is indicative of DMC-T; or, that capacity assessment has an exclusively cognitive bias, rendering it unable to accommodate the type of impairments associated with mania or other affective disorders. Capacity assessment itself should take into account not simply narrow concepts of reasoning, but all the decision-making abilities recognised by law (Dunn et al., 2006; Kim, 2009; Lepping, 2011).

Fluctuating capacity is sometimes conflated with fluctuations in mental state and preference, which can occur during states such as mania. Mania is not a static mental state and an individual's presentation, preferences and opinions may change within it. Sometimes, these changes may appear to involve coherent patterns of reasoning and increased insight. Nevertheless, even if this makes the interpretation challenging, these “fluctuations” of mental state do not indicate the types of deep changes which occur as the manic episode begins or comes to its end.

Extremely important here is also the differentiation between DMC-T and the broader notion of legal capacity. There are multiple definitions of legal capacity. However, we are using the term “legal capacity” to denote an individual's capacity to hold rights on an equal basis with

² R v C [2009] UKHL 42.

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